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ABSTRACT

Twelve 1996 issues of "Exceptional Parent" magazine provide a variety of articles and resources on parenting the child or young adult with a disability. The January issue is a resource guide, with directories of national organizations, associations, products, and services. The February issue focuses on early childhood, including articles on parents' struggles with insurance companies, daycare, and car seats and strollers. The March issue's emphasis is on mobility and includes articles on wheelchairs and transportation. The main topic of the April issue is vacation and travel, including airplane travel, accessibility struggles, and international travel. The May issue highlights recreation and includes articles on participation in sports, accessible playgrounds, the 1996 Paralympics, and sports wheelchairs. The June issue is the 25th anniversary issue and includes articles from parents on child rearing and a progress review of advocacy efforts, television awareness and access, and mobility and communication advances. How to juggle family and career is the featured topic of the July issue. The emphasis of the August issue is on health care, including articles on positive experiences with health professionals, vaccinations, alternative treatments, and managed care. The September issue features education, with articles on inclusion, myths about special education, and private education. October articles are on safe and appropriate toys for children with disabilities. Technology is the focus of the November issue. The December issue addresses living in the community, including articles on supportive housing and telemedicine. (CR)

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Exceptional Parent, 1996. Volume 26, Number 1-12.
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The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

1996 RESOURCE GUIDE

Directories of National Organizations, Associations, Products & Services

25th Anniversary 1971-1996

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JANUARY 1996 VOL. 26, ISSUE 1

EXCEPTIONAL PARENT

The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

1971-1996

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EDITOR'S DESK

Happy anniversary, EXCEPTIONAL PARENT!

25 years ago, in June 1971, the first issue of EXCEPTIONAL PARENT was distributed to several thousand parents and professionals. Our stated goal was to provide "a forum for the mutual sharing of the acquired knowledge of parents and professionals." The magazine came out bimonthly until 1984, when we increased publication to eight issues a year. EXCEPTIONAL PARENT became a monthly in 1994; each issue is now distributed to 75,000 parents and professionals.

STANLEY D. KLEIN, PH.D.

We plan a very special anniversary issue in June, but intend to celebrate our silver anniversary in every issue throughout the year—starting with this 1996 Resource Guide, our largest ever!

How to use the 1996 Resource Guide

This Resource Guide includes 10 directories containing more than 1000 resources in the United States and Canada. Each directory has been compiled with the help of caring organizations both large and small. Although we have carefully verified all the information in this Guide, a few errors undoubtedly occurred; in addition, some addresses or telephone numbers are likely to change over the course of the coming year. We welcome corrections, updates and additions for next year's Guide.

- When parents and professionals are seeking resources for a specific diagnosis, **National Resources for Specific Disabilities and Conditions** (p. 27) can help them locate appropriate national organizations for information and, in many cases, matching with other families and referrals to local resources. Because some conditions have more than one name or may be very similar to another diagnosis, this directory features extensive cross-referencing. **Matching Resources** (p. 54) may be especially useful for parents or professionals dealing with children who have extremely rare conditions or unique combinations of disabilities. Some matching groups may also be helpful when a specific diagnosis is unclear.
- For information on specific areas of concern related to children and young adults with disabilities, parents and professionals can also contact **National Information and Advocacy Resources** (p. 9) and **Federal Information Resources** (p. 111).

Children and families are usually best served in their local communities. These directories can help parents and professionals find local resources for a variety of needs:

- For local networking, parents and professionals can contact **Parent Training and Information Centers** (p. 61) and **Parent to Parent Programs** (p. 65).
- **Alliance for Technology Access Centers** (p. 82) and **State Assistive Technology Centers** (p. 85) serve as wonderful assistive technology resources in many communities.
- **Early Intervention Resources** (p. 101) can help parents and professionals obtain services for preschool children (including newborns). For public special education services, first contact your local school system; then, if necessary, contact **State Directors of Special Education** (p. 107).
- For health care and other local resources, parents and professionals can contact **University Affiliated Programs** (p. 97).

Products and Services

Today—in contrast to 1971—many fine companies and programs know that parents as well as professionals play key roles in decisions to purchase important products and services. For this reason, we encourage paid advertisements in the **Product and Services Directory** (p. 133).

Need more Resource Guides?

We are pleased to announce that the 1996 Resource Guide will be available at 130 Barnes & Nobles Superstores throughout the United States.

Twenty-five years of sharing

Since 1971, parents, family members, professionals and children and adults with disabilities have played an important part in the growth of the magazine. Our **1995 Index** illustrates the wide range of material that was covered last year. We wish everyone the very best in the new year.

EXCEPTIONAL PARENT

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

For subscription and advertising information, see page 130

BPA

Lightweight Portability Solves Transport Problem

Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

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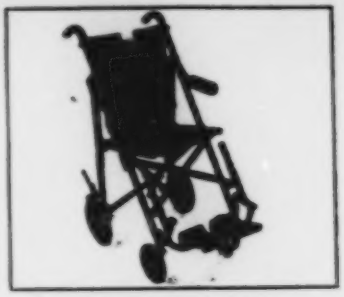

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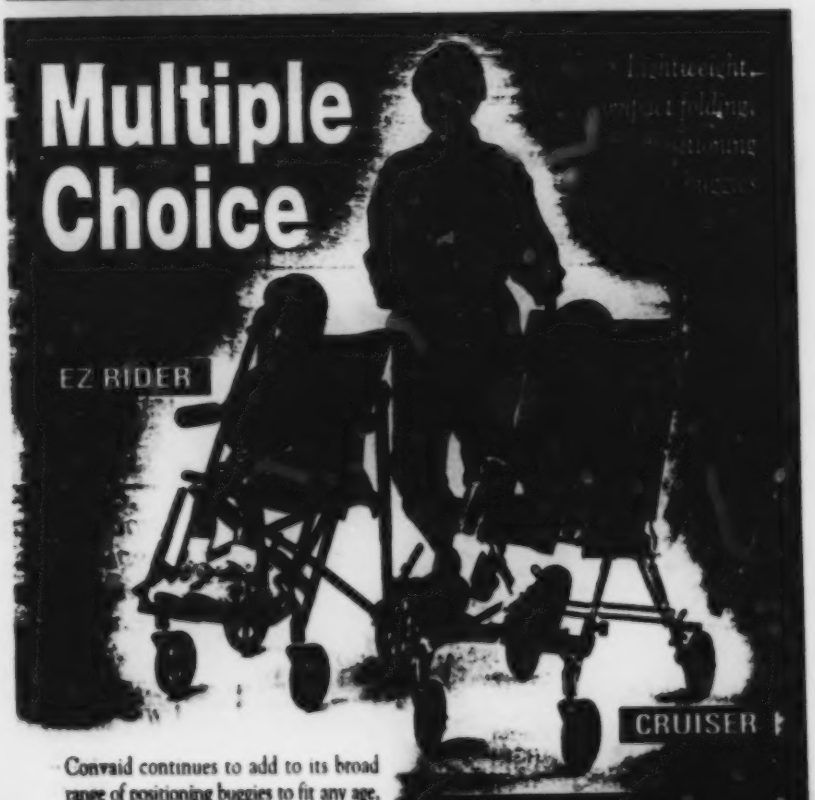

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Woodbury Products, Inc.
4410 Austin Boulevard - Dept. 250
Island Park, New York 11558

Circle #124

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- ▸ Autism & pervasive behavior disorder
- ▸ Multiple disabilities, including fetal alcohol syndrome
- ▸ Birth defects and medical/physical fragility
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301 7th Ave. NW Jamestown, ND 58401
701/252-3850 or 1-800-568-5175

Circle #128

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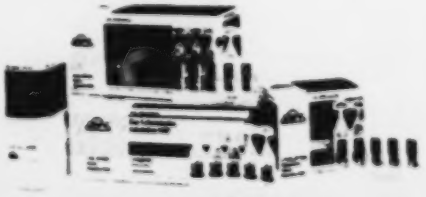

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Napa, CA 94558

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09-713-00 07/95 375-442-132-95

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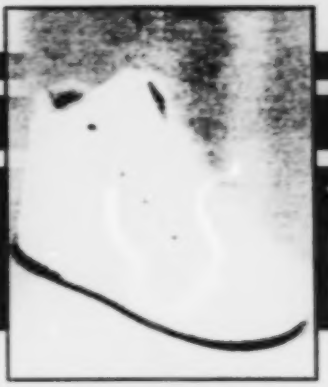

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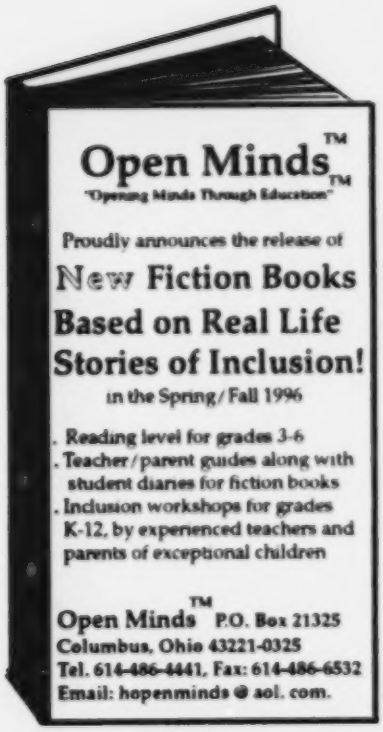

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Circle #118

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For information only	$510

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Circle #88

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National Information and Advocacy Resources

These national organizations are information and advocacy resources for families and professionals. This directory starts with a listing of organizations providing general information and advocacy, followed by organizations focusing on more specific areas of concern to the families of children and young adults with disabilities.

A description of services provided by individual organizations follows each listing. Numbers correspond to items listed in the Key to Services. This symbol (✉) indicates an Internet e-mail address; when available, organizations' World Wide Web sites are also listed.

GENERAL

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PO Box 5245
Bozeman, MT 59717
(800) 253-4091 (TTY only)
(406) 587-7421 (voice)
(406) 587-7197 (fax)
1.2.3.5
Support for parents continuing a pregnancy after a prenatal diagnosis of fatal or non-fatal birth defects.

Access Group
222 Cherokee St NE
Marietta, GA 30060
(800) 821-8580 (V/TTY)
(770) 514-7454 (V/TTY)
(770) 514-0374 (fax)
✉ bonniewebb@aol.com
1.2.5.6; Spanish materials
Offers assistive technology assistance information and equipment to families of Vietnam veterans who have children with disabilities.

American Association of University Affiliated Programs (UAPs) for Persons with Developmental Disabilities
See "University Affiliated Programs," p. 97.

Association of Birth Defect Children
827 Irma Ave
Orlando, FL 32803
(800) 313-2232 (voice; 24-hour registry line)
(407) 245-7035 (voice/fax)
1.2.3.5.7
Offers parent matching and participation in National Birth Defect Registry. Provides information about birth defects, particularly those thought to be associated with exposure to environmental toxins.

Beach Center on Families and Disability
Univ of Kansas
Inst for Life Span Studies
3111 Haworth Hall
Lawrence, KS 66045
(800) 854-4938 (voice)
(913) 864-7600 (voice)
(913) 864-7605 (fax)
✉ beachctr@dole.lsi.ukans.edu
http://kuhttp.cc.ukans.edu/cwis/units/lsi/b/beachhp.html
1.2.3.5.6.7; Spanish materials
Conducts research on family issues in families with children or teens who have disabilities or chronic illnesses.

Canadian Association for Community Living
4700 Keele St
Kinsman Bldg, York Univ
North York, ON CAN M3J 1P3
(416) 661-9611 (voice)
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
1.2.3.4.5.6.7; French materials
Provides a comprehensive disability information service. Maintains large book- and video-lending library. Advocates for inclusion and community awareness.

CAPP National Parent Resource Center
Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(617) 482-2915 (voice)
(617) 695-2939 (fax)
1.2.3.4.5.6; Spanish materials
Provides information and referrals to parents of school-age children with disabilities.

Children's Defense Fund
25 E Street NW
Washington, DC 20001
(800) 233-1200 (voice)
(202) 628-8787 (voice)
(202) 662-3520 (fax)
✉ cdfinfo@tmn.com
http://www.tmn.com/cdf/index.html
1.2.4.6; Spanish materials
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Council of Canadians with Disabilities
926-294 Portage Ave
Winnipeg, MB CAN R3C 0B9
(204) 947-0303 (voice)
(204) 942-4625 (fax)
✉ ccd@pcs.mb.ca
1.2.4.5.6; French materials
Advocates for programs that support people with disabilities, particularly people with low incomes.

DIRECT LINK for the disABLED
PO Box 1036
Solvang, CA 93464
(805) 688-1603 (V/TTY)
(805) 686-5285 (fax)
1.2.5; Spanish materials
Provides free information to individuals and families seeking help for any disability- or health-related question.

Linking Network for Kids
1101 15 St NW, Ste 1212
Washington, DC 20005
(202) 467-5730 (voice)
(202) 467-4232 (TTY)
(202) 223-0409 (fax)
1.2.4.6
Promotes community services and support to children at developmental risk from underserved families.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Ave
White Plains, NY 10605
(914) 428-7100 (voice)
2.5.6.7; Spanish materials
Provides information and referrals on birth defects, genetics and prenatal care.

Mothers from Hell
PO Box 21304
Eugene, OR 97402
1.2.5.6
Publishes a newsletter confronting disability issues with combustible humor and sentiment.

National Center for Youth with Disabilities
Univ of Minnesota
Box 721
420 Delaware St SE
Minneapolis, MN 55455
(800) 333-6293 (voice)
(612) 626-2825 (voice)
(612) 624-3939 (TTY)
(612) 626-2134 (fax)
✉ ncyd@gold.tc.umn.edu
1.2.4.6
Provides information about adolescents with chronic illnesses and disabilities and their transition to adult life, health care reform and cultural issues.

National Clearinghouse on Women and Girls with Disabilities
114 E 32nd St
New York, NY 10016
(212) 725-1803 (voice)
(212) 725-0947 (fax)
✉ 75507.1306@compuserve.com
2.5.6
Aims to increase public awareness of specific issues faced by women and girls with disabilities. Publishes manuals and directories specifically for women and girls with disabilities.

National Easter Seal Society
230 W Monroe, Ste 1800
Chicago, IL 60606
(312) 726-6200 (voice)
(312) 726-4258 (TTY)
(312) 726-1494 (fax)
http://www.seals.com
1.2.3.5.6
Local affiliates provide therapy, recreation, early intervention and vocational programs for children and teens with disabilities and their families.

National Family Caregivers Association
9621 E Bexhill Dr
Kensington, MD 20895-3104
(800) 896-3650 (voice)
(301) 942-6430 (voice)
(301) 942-2302 (fax)
1.2.3.5.6
Provides education, information, support and validation to family caregivers. Works to enhance public awareness.

National Fathers' Network
Kundering Ctr
16120 NE 8th St
Bellevue, WA 98008
(206) 747-4004 (voice)
(206) 747-1069 (fax)
✉ nfn@aol.com
1.2.3.4.5
Advocates for fathers of children with special needs through support and mentoring programs, a newsletter and working with professionals to improve service delivery.

National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions
Ctr for Developmental Disabilities
Dept of Pediatrics/USC
School of Medicine
Columbia, SC 29208
(800) 922-1107 (voice; SC only)
(800) 922-9234, ext 201 (V/TTY)
(803) 935-5250 (fax)
2.3.4.5.6; Spanish materials
Provides information and referrals to services for infants and young children with disabilities. Assists families in accessing services.

National Organization on Disability
910 16th St NW, Ste 600
Washington, DC 20006
(202) 293-5960 (voice)
(202) 293-5968 (TTY)
(202) 293-7999 (fax)
Promotes full participation of Americans with disabilities in all aspects of life including employment, community and religion. No direct services to families.

National Vaccine Information Center—Dissatisfied Parents Together
512 W Maple Ave, #206
Vienna, VA 22180
(800) 909-7468 (voice)
(703) 938-3783 (voice)
(703) 938-5768 (fax)
✉ kamvic@aol.com
1.2.3.5.6.7
Advocates for the prevention of vaccine reactions. Provides information on the Vaccine Injury Compensation Program. Makes legal referrals.

NPND- National Parent Network on Disabilities
1727 King St, Ste 305
Alexandria, VA 22314
(703) 684-6763 (V/TTY)
(703) 836-1232 (fax)
✉ npnd@aol.com
1.2.3.4.5.6; Spanish materials
Provides a national voice for parents of children and adults with disabilities. Helps parents learn ways to influence government policy.

Rural Institute on Disabilities
52 Corbin Hall
Univ of Montana
Missoula, MT 59812
(800) 732-0323 (V/TTY)
(406) 243-5467 (V/TTY)
(406) 243-4730 (fax)
1.2.4.5.6
Provides information and referral, lending library of books and videotapes, early intervention specialist training and assistive technology loan/lease program.

STOMP: Specialized Training of Military Parents
c/o Washington PAVE
12208 Pacific Highway SW
Tacoma, WA 98499
(800) 298-3543 (V/TTY)
(206) 588-1741 (V/TTY)
(206) 984-7520 (fax)
✉ pavestomp@aol.com
1.2.3.4.5
Provides information to military personnel about obtaining special education services for their children.

KEY TO SERVICES

1. Periodical newsletter
2. Informational materials
3. Networking/matching with other families
4. National conferences
5. Referrals to local resources
6. National advocacy efforts
7. Fund research

TASH: The Association for Persons with Severe Handicaps
29 W Susquehanna Ave, Ste 210
Baltimore, MD 21204
(800) 828-8274 (voice)
(410) 828-8274 (voice)
(410) 828-1306 (TTY)
(410) 828-6706 (fax)
tashbalt@aol.com
1,2,3,4,5,6
Advocates for comprehensive, high-quality, integrated education and full participation in inclusive community settings for people with disabilities.

Technical Resource Centre
1201 5th St SW, Ste 200
Calgary, AB CAN T2R 0Y6
(403) 262-9445 (voice)
(403) 262-4539 (fax)
1,2,5,6
Provides rehabilitation technology information. Special project focuses on prevention of sexual assault on women who use augmentative communication.

The Family Connection
Beach Ctr on Families and Disability
Univ of Kansas
Inst for Life Span Studies
3111 Haworth Hall
Lawrence, KS 66045
(800) 854-4938 (voice)
(913) 864-7600 (voice)
(913) 864-7605 (fax)
family@dole.lsi.ukans.edu
2,3,5; Spanish materials
Makes referrals to appropriate resources for families that have members with challenging behaviors. Provides a family-to-family network.

The HUB
Physically Disabled Service Centre
PO Box 13788
St. John's, NF CAN A1B 4G3
(709) 754-0352 (voice)
(709) 754-5125 (fax)
2,5
Clearinghouse for information on all aspects of physical disability.

World Institute on Disability
510 16th St, Ste 100
Oakland, CA 94612-1502
(510) 763-4100 (voice)
(510) 208-9493 (TTY)
(510) 763-4109 (fax)
1,2,6
Provides information to help public and private policymakers craft services and policies that support independence of people with disabilities and quality of life. Does not provide direct services.

ADOPTION

Adoptive Families of America
3333 Highway 100 N
Minneapolis, MN 55422
(800) 372-3300 (voice)
(612) 535-4829 (voice)
(612) 535-7808 (fax)
1,2,3,4,5,6
Provides problem-solving assistance and information to members of adoptive families and prospective adoptive families.

Jewish Children's Adoption Network
PO Box 16544
Denver, CO 80216-0544
(303) 573-8113 (voice)
(303) 893-1447 (fax)
1,2,3,5,6
Helps birth and adoptive families find resources to help them parent children with disabilities. Finds adoptive placements for waiting children.

National Adoption Center
1500 Walnut St, Ste 701
Philadelphia, PA 19102
(800) 862-3678 (voice)
(215) 735-9988 (voice)
(215) 735-9410 (fax)
nac@netcom.net
http://www.adopt.org/adopt
1,2,5,6
Approved adoptive families may register on National Adoption Exchange, a computerized database of waiting minority children and children with disabilities, and families hoping to adopt such a child.

National Adoption Information Clearinghouse
5640 Nicholson Ln, Ste 300
Rockville, MD 20852
(301) 231-6512 (voice)
(301) 984-8527 (fax)
2,5,6
Provides information on adopting children with disabilities.

ARCHITECTURAL ACCESSIBILITY

Adaptive Environments Center
374 Congress St, Ste 301
Boston, MA 02110
(617) 695-1225 (V/TTY)
(617) 482-8099 (fax)
adaptive@interramp.com
2,5
Promotes accessibility through educational programs, technical assistance and publications.

Center for Universal Design
North Carolina State Univ
School of Design
Box 8613
Raleigh, NC 27695-8613
(800) 647-6777 (V/TTY)
(919) 515-3082 (V/TTY)
(919) 515-3023 (fax)
cahds@ncsu.edu
2
Provides design information and assistance for construction of new housing and home modifications.

ASSISTIVE TECHNOLOGY

See also: Assistive Technology/Legal Resources

Activating Children Through Technology
27 Horrabin Hall
Western Illinois Univ
Macomb, IL 61455
(309) 298-1634 (voice)
(309) 298-2305 (fax)
1,2,4
Provides training and resource information to families of children birth to eight years, on integrating technology into individual educational programs (IEPs).

Project Link
515 Kimball Tower
SUNY at Buffalo
3435 Main St
Buffalo, NY 14214
(800) 628-2281 (V/TTY)
(716) 829-3141 (V/TTY)
(716) 829-3217 (fax)
http://cosmos.ot.buffalo.edu
1,2,4,5,6,7; Spanish/Portugese/Japanese/Russian materials
Provides information about assistive technology and assistive devices.

Techknowledge
Georgia Inst of Technology
Atlanta, GA 30332-0156
(800) 726-9119 (voice)
(404) 894-4960 (voice)
(404) 853-9320 (fax)
robert.todd@arch.gatech.edu
1,2,5,6,7
Provides free information on products and resources through 800-number.

Tele-Consumer Hotline
901 15th St NW, Ste 230
Washington, DC 20005
(202) 347-7208 (V/TTY)
2,5; Spanish materials
Provides free information about equipment and phone services for consumers with speech, vision, hearing or mobility impairments.

ASSISTIVE TECHNOLOGY/LEGAL RESOURCES

Ability Access
613 E Grand Ave
Escondido, CA 92025
(800) 858-5116 (voice)
(619) 480-7367 (voice)
(619) 480-0249 (fax)
1,2,3,5,6
Provides legal referrals for persons dealing with access-to-technology issues.

CHILD CARE

See also: Child Care/Legal Resources

Child Care Plus
Rural Inst on Disabilities
52 N Corbin Hall
Univ of Montana
Missoula, MT 59812
(800) 235-4122 (V/TTY)
(406) 243-5467 (V/TTY)
(406) 243-4730 (fax)
1,2,5,6
Provides technical assistance, written materials and training for families, child care providers and others who support inclusion in early childhood programs.

SpecialLink
PO Box 775
Sydney, NS CAN B1P 6G9
(800) 840-5465 (voice, Canada only)
(902) 562-1662 (voice)
(902) 539-9117 (fax)
srwinn@fox.nstn.ca
1,2,4,6; French materials
Serves as the hub of a 4,000-person network of Canadian advocates for early intervention, inclusive childcare and education. Provides resources and referrals. Promotes inclusive practices, policies and programs.

Here she comes! **Jackie Comerford**, 13, of Oswego, New York, sneaks up on her twin cousins **Joshua and Claire Mann**, 8 months. Jackie loves it when the twins drop over for a visit! Jackie attends an inclusive sixth grade classroom at the Minetto School, where she is an enthusiastic member of the computer club. Jackie, who has cerebral palsy and attention deficit disorder, also enjoys swimming and rollerblading.

CHILD CARE/LEGAL RESOURCES

Child Care Law Center
22 Second St, 5th Fl
San Francisco, CA 94105
(415) 495-5498 (voice)
(415) 495-6734 (fax)
1,2,5,6; Spanish/Chinese materials
Educates parents about their child care rights under the Americans with Disabilities Act (ADA).

DISABILITY AWARENESS

Kids on the Block
9385-C Gerwig Ln
Columbia, MD 21046
(800) 368-5437 (voice)
(410) 290-9095 (voice)
(410) 290-9358 (fax)
Provides disability awareness curricula for local communities using puppets, scripts and follow-up activities.

EDUCATION

National Coalition of Title I/ Chapter 1 Parents
Edmonds School Bldg, Rm 201
9th & D St NE
Washington, DC 20002
(202) 547-9286 (voice)
(202) 544-2813 (fax)
1,4,6
Provides information and training to help parents participate in planning, implementing and evaluating local Title I programs.

EMPLOYMENT

Association for Persons in Supported Employment
1627 Monument Ave
Richmond, VA 23220
(804) 278-9187 (voice)
(804) 278-9377 (fax)
1,2,4,5
Works to expand integrated employment opportunities for persons with disabilities.

Goodwill Industries of America
9200 Wisconsin Ave
Bethesda, MD 20814
(301) 530-6500 (voice)
(301) 530-1516 (fax)
cmoeller@goodwill.org
1,2,4,5,6
Provides job skill training and job placement assistance to people with disabilities.

Job Opportunities for the Blind
National Ctr for the Blind
1800 Johnson St
Baltimore, MD 21230
(800) 638-7518 (voice)
(410) 659-9314 (voice)
(410) 685-5653 (fax)
http://www.nfb.org
1,3,4,5,6,7
Free information packet. Nationwide networking and referral services.

Mainstream
3 Bethesda Metro Ctr, Ste 830
Bethesda, MD 20814
(301) 654-2400 (V/TTY)
(301) 654-2403 (fax)
mainstrm@aol.com
1,2,4,5
Provides information on nationwide employment opportunities for individuals with disabilities. Provides direct job-placement services in Washington, DC and Dallas, TX.

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching with other families
4 National conferences
5 Referrals to local resources
6 National advocacy efforts
7 Fund research

Opening The Door To Success

... in seven weeks.

Throwing items, turning over furniture, pulling hair ... the list continues. For Adam, summers mean more than hayrack rides and swimming. They mean concentrated training, lifeskills, and measurable gains through Heartspring's Summer Intensive Behavior Program.

Adam, 10, has autism and during his first few days of the summer program at Heartspring, he averaged about 45 acting-out episodes a day. Heartspring staff members developed a plan to interrupt destructive and aggressive behaviors and to teach Adam more appropriate ways to communicate his needs and frustrations.

They used reinforcers, such as Adam's favorite foods, raisins and apples, and a trip to the local amusement park. A special picture system was developed to help Adam communicate his wants and express his feelings. His program also included around-the-clock extensive behavior management. By the end of the seven weeks, Adam's daily episodes of acting-out had decreased nearly 90 percent.

And what do Adam's parents have to say about the program? "We were pleased with the growth our son exhibited. Heartspring's summer program met Adam's needs in a diverse way that no other program we've looked at could."

To learn how this very special program can benefit your child, call us today.

Heartspring's Summer Intensive Behavior Program
1996 Session: June 17 to August 1
Application deadline: March 1, 1996

HEARTSPRING℠

Building a brighter future for children

2400 JARDINE DRIVE ♦ WICHITA, KANSAS 67219-4699

1-800-835-1043

Circle #158

For more information on Apple products, contact us at 800-600-7808, 800-755-0601 (TTY), or on the Internet at applewdsg@eworld.com.

Apple

HEALTH CARE

Association for the Care of Children's Health
7910 Woodmont Ave, Ste 300
Bethesda, MD 20814
(800) 808-2224, ext 306 (voice)
(301) 654-6549, ext 306 (voice)
(301) 986-4553 (fax)
acch@clark.net
1,2,4,5,6
Organization of family members and professionals. Advocates for family-centered care for children needing specialized health and developmental services. Offers a forum for information sharing and peer support.

Children's Hospice International
1850 M St NW, Ste 900
Washington, DC 20036
(800) 242-4453 (voice)
(703) 684-0330 (voice)
(703) 684-0226 (fax)
1,2,4,5,6
Offers medical, technical and educational support to health care professionals and the families of children needing hospice care.

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913 (voice)
(317) 872-0795 (fax)
1,2,3,4,5
Advocates for family-centered services and provides social, emotional and informational support to families and caregivers involved in neonatal intensive care.

Center for Children with Chronic Illness and Disability
Univ of Minnesota
Box 721 UMHC
420 Delaware St SE
Minneapolis, MN 55455
(612) 626-4032 (voice)
(612) 624-3939 (TTY)
(612) 626-2134 (fax)
c3id@gold.tc.umn.edu
1,2,4,5,6
Seeks to increase and apply knowledge that fosters the physical, psychological and social development of infants, children and adolescents with chronic illnesses and disabilities and their families.

INDEPENDENT LIVING

Canadian Association of Independent Living Centers
350 Spark St, Ste 1004
Ottawa, ON CAN K1R 7S8
(613) 563-2581 (V/TTY)
(613) 235-4497 (fax)
1,2,4; French materials
Umbrella organization of Canadian independent living resource centers.

Independent Living Research Utilization Program
2323 S Shepherd, Ste 1000
Houston, TX 77019
(713) 520-0232 (voice)
(713) 520-5136 (TTY)
(713) 520-5785 (fax)
1,2,5; Spanish materials
Maintains directories of independent living (IL) centers, of people who provide IL technical assistance and of IL support materials.

LEGAL RESOURCES

See also: Assistive Technology: Legal Resources, Child Care: Legal Resources

American Bar Association Center on Children and the Law
740 15th St NW, 9th Fl
Washington, DC 20005-1009
(202) 662-1720 (voice)
(202) 662-1755 (fax)
ctrchildlaw@attmail.com
1,6,7
Publishes information about legal issues related to children.

DREDF: Disability Rights Education and Defense Fund
2212 6th St
Berkeley, CA 94710
(800) 466-4232 (V/TTY)
(510) 644-2555 (V/TTY)
(510) 841-8645 (fax)
1,2,3,5,6
Offers training, information and legal advocacy to parents of children with disabilities to help them secure appropriate educational and other services. Offers information and referrals by phone.

Judge David Bazelon Center for Mental Health Law
1101 15th St NW, Ste 1212
Washington, DC 20005
(202) 467-5730 (voice)
(202) 467-4232 (TTY)
(202) 223-0409 (fax)
1,2; Spanish materials
Uses litigation and federal policy reform to define and uphold legal rights of children and adults with mental illness. Provides training and technical assistance to other programs.

National Association of Protection and Advocacy Systems
900 2nd St NE, Ste 211
Washington, DC 20002
(202) 408-9514 (voice)
(202) 408-9521 (TTY)
(202) 408-9520 (fax)
hn4537@handsnet.org
1,2,4,5,6
Voluntary membership organization of federally-mandated programs advocating for the rights of people with disabilities. Offers referrals to programs in each state and territory.

Pike Institute on Law and Disability
Boston Univ School of Law
765 Commonwealth Ave
Boston, MA 02215-1620
(617) 353-2904 (V/TTY)
(617) 353-2906 (fax)
pikeinst@bu.edu
1,2,5,6
Provides information and referrals for disability-related legal matters.

RARE DISORDERS

See "Matching Resources," p. 54

REHABILITATION

Canadian Rehabilitation Council for the Disabled
45 Sheppard Ave E, Ste 801
Willowdale, ON CAN M2N 5W9
(416) 250-7490 (voice/TTY)
(416) 229-1371 (fax)
1,2,5,6
Umbrella organization of Canadian service providers, health professionals and consumer groups.

RESPITE CARE

ARCH National Resource Center
800 Eastowne Dr, Ste 105
Chapel Hill, NC 27514
(800) 773-5433 (voice)
(919) 490-4905 (fax)
1,2,4,5
Free national respite-provider locator service through 800-number listed above.

SELF-HELP

American Self-Help Clearinghouse
Northwest Covenant Medical Ctr
Denville, NJ 07834-2995
(800) 367-6274 (NJ only)
(201) 625-7101 (voice)
(201) 625-9053 (TTY)
(201) 625-8848 (fax)
amershc@aol.com
3,5
Provides referrals to and information on starting national support groups and local self-help clearinghouses.

National Self-Help Clearinghouse
CUNY Grad School, University Ctr
25 W 43rd St, Rm 620
New York, NY 10036
(212) 354-8525 (voice)
(212) 642-1956 (fax)
1,5
Provides referrals to support groups and self-help clearinghouses. Provides information on starting support groups.

SEXUALITY

Sexuality Information and Education Council of the US
130 W 42nd St, Ste 350
New York, NY 10036
(212) 819-9770 (voice)
(212) 819-9776 (fax)
1,2,6; Spanish materials
Does database searches of library's extensive holdings on sexuality and disability.

SIBLING SUPPORT

Sibling Information Network
249 Glenbrook Rd
PO Box U64
Storrs, CT 06269-2064
(860) 486-4985 (voice)
(860) 486-5037 (fax)
1,2,5
Clearinghouse of information related to siblings of individuals with disabilities.

TRAVEL

Mobility International USA
PO Box 10767
Eugene, OR 97440
(541) 343-1284 (V/TDD)
(541) 343-6812 (fax)
miusa@igc.apc.org
1,2,4,5,6
Provides international educational travel and leadership development opportunities for youth and adults with disabilities. Coordinates educational exchanges with other countries. Offers travel information and referral services for people with disabilities and their families.

Society for the Advancement of Travel for the Handicapped
347 5th Ave, Ste 610
New York, NY 10016
(212) 447-7284 (voice)
(212) 725-8253 (fax)
1,2,6
Provides information about accessible recreation and travel facilities, including those designed specifically for children and young adults.

Travel Information Service
Moss Rehab Hosp
1200 W Tabor Rd
Philadelphia, PA 19141
(215) 456-9600 (voice)
(215) 456-9602 (TTY)
5
Provides free telephone information on travel accessibility.

WISH ORGANIZATIONS

Brass Ring Society
500 Macaw Ln, #5
Fern Pk, FL 32730
(800) 666-9474 (voice)
(407) 339-6369 (fax)
brassring@brassring.org
http://www.brassring.org/brassring
1,2
Fulfills wishes for children with life-threatening illnesses.

Children's Hopes and Dreams Foundation
280 Rt 46
Dover, NJ 07801
(201) 361-7366 (voice)
(201) 361-6627 (fax)
1,3
Fulfills wishes for children, ages 4–17, with life-threatening or chronic illnesses. Worldwide pen pal program for children with illnesses or disabilities.

Children's Wish Foundation International
7840 Roswell Rd, Ste 301
Atlanta, GA 30350
(800) 323-9474 (voice)
(770) 393-9474 (voice)
(770) 393-0683 (fax)
1,2,4
Fulfills wishes for children with life-threatening illnesses. Provides emergency financial aid for medical expenses.

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching with other families
4 National conferences
5 Referrals to local resources
6 National advocacy efforts
7 Fund research

Grant A Wish Foundation
c/o Brian Morrison
PO Box 21211
Baltimore, MD 21228
(800) 933-5470 (voice)
(410) 242-1549 (voice)
(410) 242-8818 (fax)
grantawish@aol.com
1,2,5
Provides on-going programs aimed at reducing stress and anxiety in the lives of children being treated for life-threatening illnesses. Programs include support groups, wilderness retreats, in-hospital entertainment and granting of wishes.

Lisa Madonia Memorial Fund
409 Beloit
Forest Park, IL 60130
(708) 366-2057 (voice)
(708) 366-2065 (fax)
lmmfi@aol.com
1,2,3,5
Fulfills wishes for young people, ages 18–25, with cancer.

Make-a-Wish Foundation of America
100 W Clarendon, Ste 2200
Phoenix, AZ 85013-3518
(800) 722-9474 (voice)
(602) 279-9474 (voice)
(602) 279-0855 (fax)
2,4,5
Fulfills wishes for children with life-threatening illnesses.

Sunshine Foundation
2001 Bridge St
Philadelphia, PA 19124
(800) 767-1976 (voice)
(215) 535-1413 (voice)
(215) 535-8397 (fax)
2,3,4
Fulfills wishes for children, ages 3–21, with disabilities or chronic or life-threatening illnesses.

The Children's Wish Foundation
1735 Bayly St, Ste 8C
Pickering, ON CAN L1W 3G7
(800) 267-9474 (voice)
(905) 420-4055 (voice)
(905) 831-9733 (fax)
1,2,4,5
Fulfills wishes for Canadian children, ages 3–18, with life-threatening illnesses.

The Dream Factory
315 Guthrie Gt
Louisville, KY 40202
(800) 456-7556 (voice)
(502) 584-3928 (voice)
(502) 584-0023 (fax)
2,4
Fulfills wishes for children with critical or chronic illnesses.

BEST COPY AVAILABLE

General Motors.

GM MOBILITY PROGRAM

"The GM Mobility Program can help you a lot. I know because my mom is part of it."

General Motors Corporation © 1994

An active honor roll student, Tammie Groth doesn't believe in obstacles. Neither does her mother, Connie, one of the many General Motors employees whose own lives are affected by physical disability. It's their valuable insights that help make the GM Mobility Program work. Transportation means independence. That's something the people at General Motors know from their own experience.

Call the GM Mobility Assistance Center. We'll give you: • The names of local companies that provide driver assessment services, adaptive driving devices and vehicle modifications. • An informative videotape, "On the Move Again." • Suggestions for the General Motors cars and trucks that might work best for you. Then, if you buy or lease a new GM vehicle, we'll reimburse you up to $1000 toward the cost of adapting it or reinstalling your own adaptive equipment. Call 1-800-323-9935 (TDD users: 1-800-TDD-9935), or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer to find out more.

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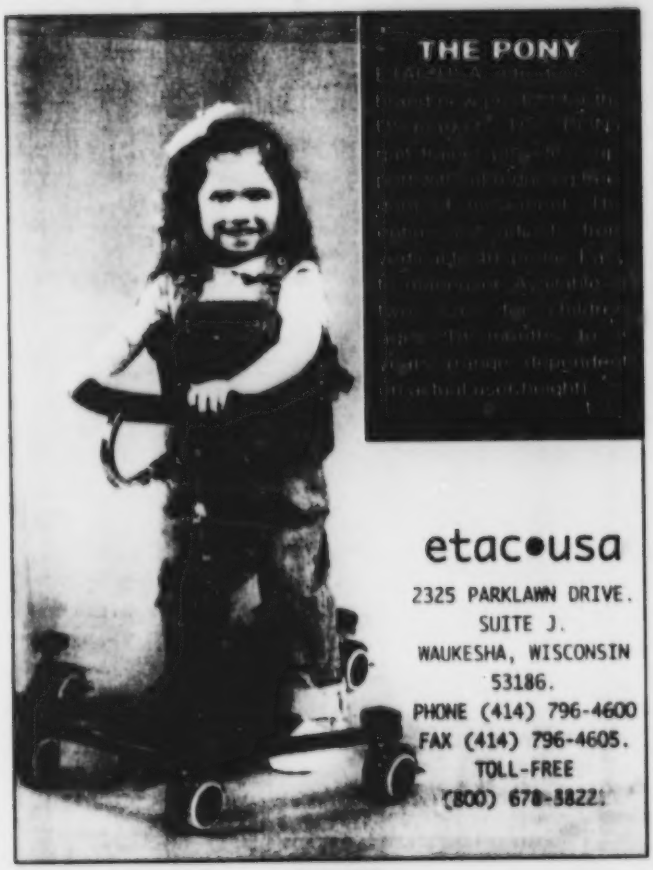

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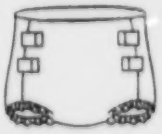
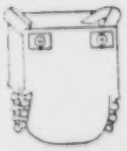


Adult/Youth Briefs



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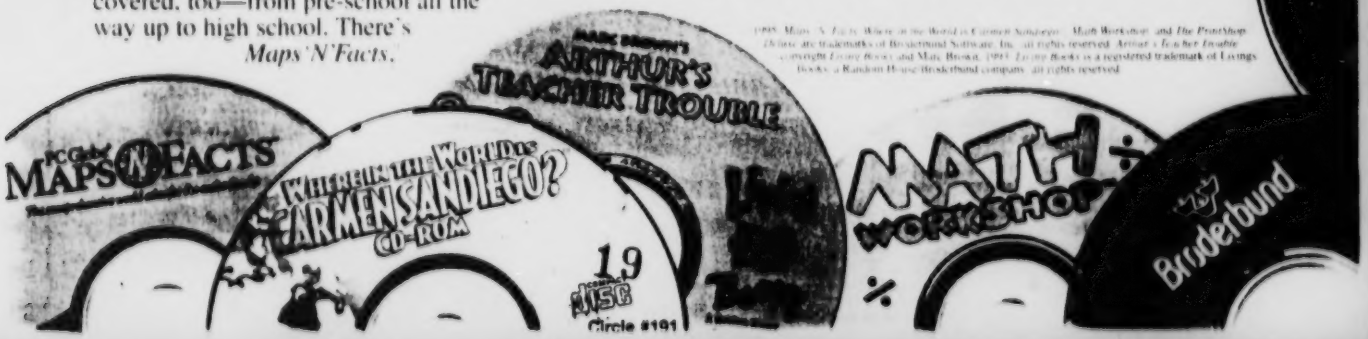

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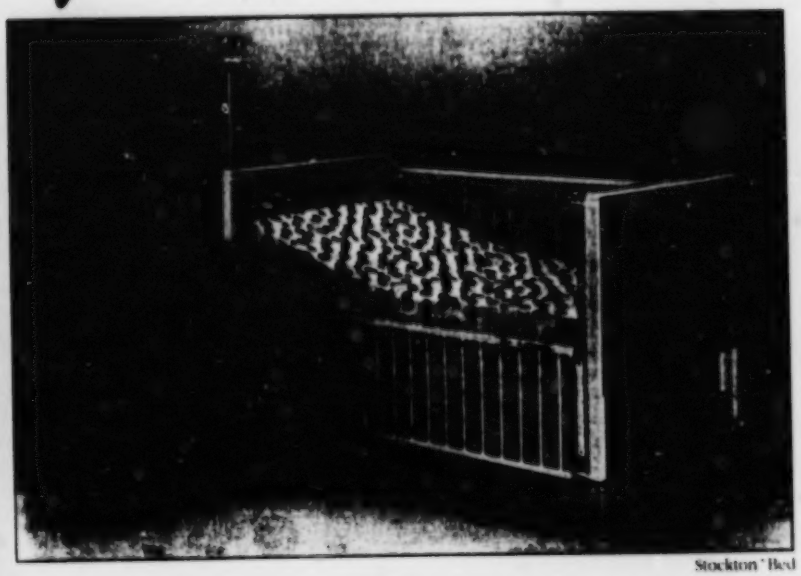

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EXCEPTIONAL PARENT is the magazine for parents and professionals involved in the care and development of children and young adults with special needs including:

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Autism, Epilepsy
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Perceptual Disabilities
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EXCEPTIONAL PARENT'S mission is to:

PROVIDE practical guidance and support for parents, educators and professionals caring for children and young adults with disabilities and special health care needs.

INFORM parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities and their families

SERVE as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators

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Must reading for all those with a handicapped child...a boon to parents... it could change their lives."
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T. Berry Brazelton,
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Circle #99

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Record Capacity	1.5 minutes	3 minutes
Number of Messages	15 msgs	30 msgs
Available Levels	1 level	2 levels
Auditory Scanning Manual or Automatic (selectable rate)	Yes	Yes
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Overall Size	3.75" wide x 6.5" long	

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B R A U N

Proven by over 20 years of use in the mobility marketplace, you can count on the quality and dependability of the original Braun Lift-A-Way® lift.

The fully automatic rear post Swing-A-Way® lift provides the widest clear path access in the industry for passengers and cargo.

The new Lift-A-Way D/C® is the latest in the Braun line of wheelchair lifts. The ARS engages before there is any vertical platform movement.

The Braun Chair Topper® car top wheelchair carrier is available in the driver's side configuration or the optional passenger side design.

Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle rebates are also listed in this comprehensive booklet.

"Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

Entervan™

The reliability and performance of the new electromechanical kneeling system sets the Braun Entervan™ apart from other low floor conversions. The Braun Corporation has a large selection of Entervans™ in stock, converted and ready for delivery. Rounding out Braun's complete mobility package, the new rear-entry Windstar Entervan™ is the economical choice for the couple or small family.

International Leader in Personal Mobility Products

The Braun Corporation has established their products as the benchmark for International Personal Mobility. Now, with the introduction of the exclusive electromechanical kneeling system, the Braun Entervan™ offers a new level of reliable mobility.

The electromechanical non-air kneeling system automatically lowers the rear of the vehicle while the door is opening. This design utilizes Chrysler coil springs instead of airbags, and automatically returns to normal driving height when the door closes or when the vehicle is taken out of park. Even in the event of electrical failure, the mechanical override will return the vehicle from the kneeled position.

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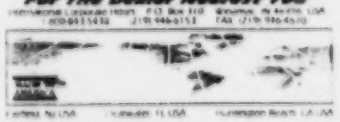

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The Braun Corporation is the international leader in mobility products. With four divisions and a worldwide All-Star Distributor network, we are positioned to provide the equipment and service you need. Our commitment to your satisfaction is also supported by our Three-Year Worry-Free Limited Warranty. Simply call 1-800-THE LIFT for the Braun All-Star nearest you.

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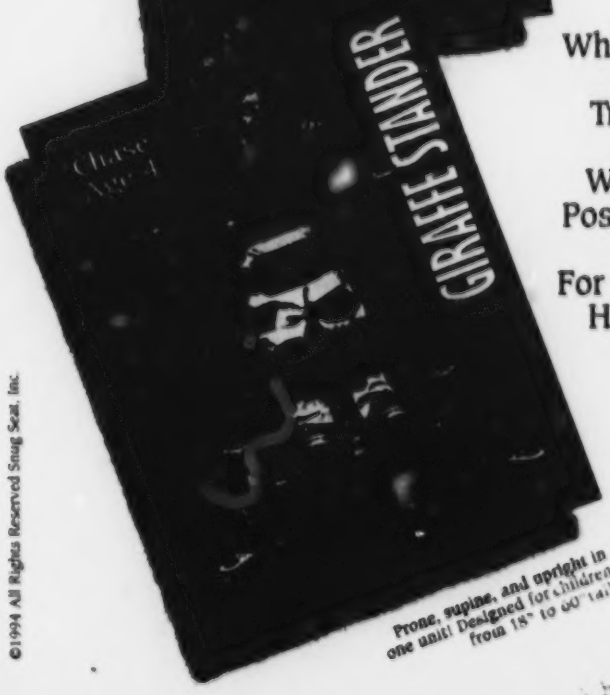

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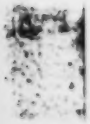

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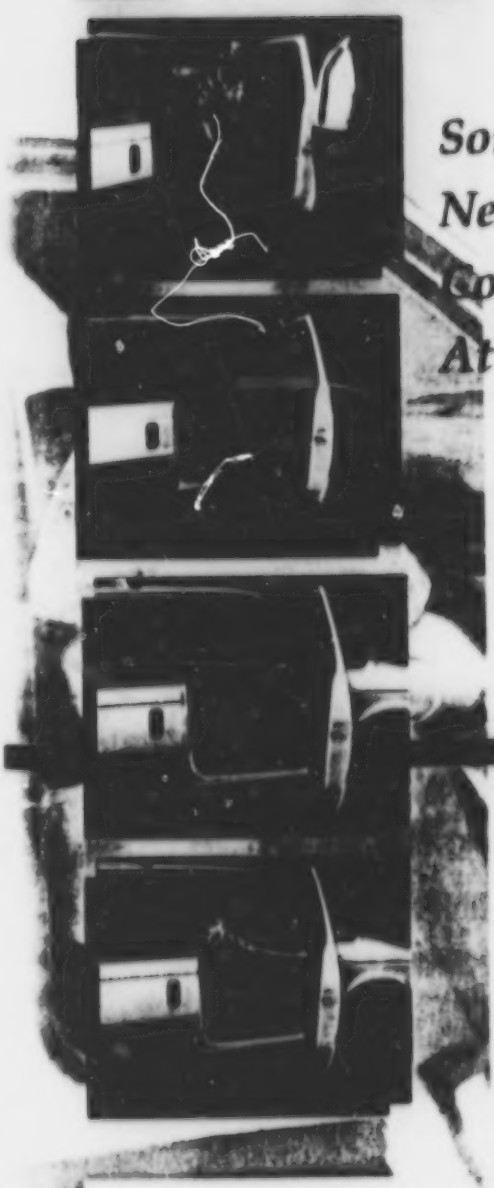

Something New Is Coming Out At Braun...

The Perfect Companion

The Braun Companion Seat®

If you have difficulty entering and exiting your vehicle, the new Companion Seat® is your key to greater mobility. Its automatic operation and rugged construction enable semi-ambulatory persons to reliably and conveniently board Dodge Caravan or Plymouth Voyager minivans.

The seat extends 20" and tilts forward a full 6" to make boarding safe and easy. Once on the seat, you are smoothly raised into the vehicle by pressing the conveniently mounted switch. All you have left to do is manually rotate into the forward facing position. To exit, the procedure is simply reversed.

The Companion Seat® utilizes your van's original seat, but replaces the existing seat base with a unique power base. When not needed, it functions exactly as the passenger seat. This feature makes it perfect for active families with only one member who needs assistance. And, as always, Braun thoroughly tested the Companion Seat® to meet all applicable federal motor vehicle safety standards.

If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braun distributor about other sources of assistance.

For more information on the Companion Seat® or other Braun mobility products, call us today at 1-800-THE LIFT. We will give you the name and location of distributors in your area.

Now more than ever, mobility is one of the most important things in your life. Let Braun and the Companion Seat® be the answer to your needs.

Patents Pending

Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle rebates are also listed in this comprehensive booklet. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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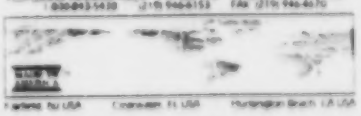

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The pamphlet "Swallowing Problems" helps patients and caregivers understand and adapt to dysphagia.

Circle #235

A+

Exceptional Children Deserve
An Exceptional Stroller

Children are exceptional and deserve exceptional opportunities. To go and to do. To explore the world around them.

The new Cub™ Pediatric gives your child the freedom to plan his or her own personal voyages of discovery.

The Cub is easy for a child to use, with a compact width that permits exceptionally tight turns. And the Cub is available in front or rear drive.

Each Cub Pediatric includes an Adaptable Seat, for exceptional comfort. Seating and positioning are critical for a growing child.

Proportional Sizing™ is also standard, because no two children are the same and no two diagnoses are identical. Bruno believes your child is entitled to an exceptional fit and support.

And the Cub offers a rainbow of exceptional color choices: bubblegum pink, emerald green, electric blue, cranberry red and viper yellow.

■ Please call 1-800-882-8183, or 1-414-567-4990 for a free product video and Cub brochure.

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Circle #240

MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some new ways to give time a hand.

THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

And now (finally!), there are pants you can buy that can make a real difference at your house, every night and every morning. Your child will still wet. He can't help it. But from now on, that doesn't have to mean he has to wet the bed.

TOMORROW CAN BE DIFFERENT

The makers of Pull-Ups® training pants have invented the first and only disposable underpants for larger children, 45 to 85+ pounds.

Pull-Ups® GoodNites® disposable absorbent underpants eliminate the rubber sheets and the laundry and much of the stress that make nighttime accidents into a bigger deal than they really are, and make our children feel small. Smaller than they really are.

GoodNites look a lot like plain white underpants, except slightly thicker. They come in two sizes and even have a label in the back. The trim fit helps GoodNites underpants vanish discreetly under pajamas, while the super absorbent middle is ready, just in case. In every detail, the GoodNites people have done everything possible to make these absorbent underpants respect our kids like the grown-ups they soon will be.

THE WAY THINGS SHOULD BE

If yours is already a GoodNites family, there's some good news for you, too. GoodNites are now even more absorbent than before.

If GoodNites underpants are new to you, now is the time to try them. You will rejoice that you did.

GoodNites are not a miracle, but there's nothing like them. They help families keep bed-wetting in perspective. They help make dry mornings, in crisp clean sheets, routine. And make sleep-overs and other normal, healthy everyday kid things routine, too. The way they should be.

THE GOODNITES GUIDES

GoodNites underpants were developed with the help of pediatricians and other childhood specialists. You'll find much of their good advice in these little booklets. One is written for parents. The other is for your child. For copies, please send $1 for postage and handling to: GoodNites Guides, P.O. Box 1165, Maple Plain, MN 55592.

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Circle #253

National Resources for Specific Disabilities and Conditions

This directory includes national groups and organizations that can serve as resources for parents and professionals seeking information and support regarding specific disabilities and conditions. Please note that information on some specific disabilities may also be available from Federal and Federally-Funded Information Resources (pp 111-112), Parent to Parent Programs (pp 65-70) or certain National Information and Advocacy Resources (pp 9-12). In addition, Matching Resources (p 54) may be useful for parents who have children with extremely rare conditions or unique combinations of disabilities.

CROSS-REFERENCING

To enable readers to find all relevant resources for a specific disability or condition, disability categories have been cross-referenced where appropriate.

Many conditions are known by more than one name. Relevant resources will be listed under only one name; but synonyms for that condition will also appear in the directory, each with a note directing readers to "see" the name under which resources are listed. (Under CHROMOSOME 4P- for example, readers are referred to WOLF-HIRSCHHORN SYNDROME.)

To the best of our knowledge, however, some specific disabilities do not have a disability-specific national organization. These conditions may be cross-referenced to a broader category containing organizations that provide resources for that condition as well as others. (For example, the metabolic condition ARGINASE DEFICIENCY is cross-referenced to UREA CYCLE DISORDERS.) In some cases, a condition for which there is no disability-specific national organization may be cross-referenced to a similar (but not identical) condition, when groups for that condition have indicated the ability and willingness to provide appropriate information and support. (For example, several male sex chromosome disorders other than 47,XXY are cross-referenced to KLINEFELTER SYNDROME.)

In cases where resources are available for both a general category of disability (for example, VISUAL IMPAIRMENTS), as well as specific conditions within that general category (for example, ALBINISM; GLAUCOMA; MACULAR DISEASES; RETINITIS PIGMENTOSA; RETINOBLASTOMA; RETINOPATHY OF PREMATURITY; SEPTO-OPTIC DYSPLASIA; STARGARDT DISEASE and USHER SYNDROME), cross-referencing goes in two directions. For example, under VISUAL IMPAIRMENTS, readers are informed of the types of visual impairments for which specific resources exist; and under each specific type of visual impairment, readers are referred back to the more general category. (The only exception to this type of cross-referencing is the general category MENTAL RETARDATION. Because mental retardation is a common feature of many specific syndromes and conditions, space limitations precluded the use of MENTAL RETARDATION as a cross-referencing term.)

In cases where one specific condition usually includes other conditions, but those other conditions do not necessarily include the first condition, cross-referencing goes in one direction only. For example, under LAURENCE-MOON-BARDET-BIEDL SYNDROME, readers are directed to "see also" KIDNEY DISORDERS and RETINITIS PIGMENTOSA. But neither KIDNEY DISORDERS nor RETINITIS PIGMENTOSA refers readers back to Laurence-Moon-Bardet-Biedl syndrome (LMBBS). This is because, in addition to mental retardation and obesity, LMBBS typically includes kidney complications and the progressive visual loss known as retinitis pigmentosa. However, LMBBS is not cross-referenced under KIDNEY DISORDERS or RETINITIS PIGMENTOSA because a primary diagnosis of one of these conditions does not typically include LMBBS.

Cross-referencing assistance came from the organizations listed in this directory and from the *Physician's Guide to Rare Diseases* (second edition, 1995), edited by Jess G. Thoene, M.D., which is available from Exceptional Parent Library (800/535-1910).

USING THIS DIRECTORY

A description of services provided by individual groups follows each listing in this directory. Numbers correspond to items listed in the Key to Services. This symbol (✉) indicates an Internet e-mail address; when available, an organization's World Wide Web site is also listed. Unless otherwise indicated, telephone numbers are for voice only.

11-B-HYDROXYLASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

17-20-DESMOLASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

17-ALPHA-HYDROXYLASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

17-HYDROXYLASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

21-HYDROXYLASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

3-B-HYDROXYSTEROID DEHYDROGENASE DEFICIENCY

See: Adrenal Hyperplasia, Congenital

45,X SYNDROME

See: Turner Syndrome

A-BETA-LIPOPROTEINEMIA

See: Tay-Sachs Disease

AARSKOG SYNDROME

See also: Growth Disorders

Aarskog Syndrome Parent Support Group
c/o Shannon Caranci
62 Robin Hill Ln
Levittown, PA 19055-1411
(215) 943-7131
1,2,3,9

AARSKOG-SCOTT SYNDROME

See: Aarskog Syndrome

ABDOMINAL MIGRAINE

See: Cyclic Vomiting Syndrome

ACID MALTASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

ACIDEMIA, ISOVALERIC (IVA)

See: Acidemia, Organic

ACIDEMIA, METHYLMALONIC

See: Acidemia, Organic

ACIDEMIA, ORGANIC

See also: Fatty Oxidation Disorder; Maple Syrup Urine Disease; Metabolic Disorders

Organic Acidemia Association
c/o Carol Barton
2287 Cypress Ave
San Pablo, CA 94806
(510) 724-0297
1,3,4,5

ACIDEMIA, PROPIONIC

See: Acidemia, Organic

ACOUSTIC NEUROMA

See also: Balance Disorders & Dizziness; Brain Tumors; Hearing Impairments; Neurofibromatosis; Neurofibromatosis, Type 2; Vestibular Disorders

Acoustic Neuroma Association
PO Box 12402
Atlanta, GA 30355
(404) 237-8023
(404) 237-2704 (fax)
1,2,3,4,5,6,9

Acoustic Neuroma Association of Canada
PO Box 369
Edmonton, AB CAN T5J 2J6
(800) 561-2622 (V/TTY, Canada only)
(403) 428-3384 (V/TTY)
1,2,3,4,5,6,7,8; French materials

ACQUIRED IMMUNE DEFICIENCY SYNDROME

See: AIDS

ACROCEPHALOSYNDACTYLY, TYPE I

See: Apert Syndrome

ACROCEPHALOSYNDACTYLY, TYPE II

See: Crouzon Disease

ACROFACIAL DYSOSTOSIS, NAGER TYPE

See: Nager & Miller Syndromes

ACROMEGALY

See: Multiple Endocrine Neoplasia I; Pituitary Tumors

ACTH DEFICIENCY

See: Adrenal Disorders; Pituitary Disorders

ACYL-COA DEHYDROGENASE DEFICIENCY, MEDIUM-CHAIN

See: Fatty Oxidation Disorder

ADDISON DISEASE

See: Adrenal Disorders; Adrenal Hyperplasia, Congenital

ADIPOGENITAL-RETINITIS PIGMENTOSA-POLYDACTYLY SYNDROME

See: Laurence-Moon-Bardet-Biedl Syndrome

ADRENAL CORTEX MALE PSEUDOHERMAPHRODITISM

See: Adrenal Hyperplasia, Congenital

ADRENAL DISORDERS

See also: Adrenal Hyperplasia, Congenital

National Adrenal Diseases Foundation
505 Northern Blvd
Great Neck, NY 11021
(516) 487-4992
http://medhlp.netusa.net/www/nadf.htm
1,2,3,4,5

ADRENAL HYPERPLASIA, CONGENITAL

See also: Adrenal Disorders; Genitalia, Ambiguous; Growth Disorders; Hermaphroditism

Congenital Adrenal Hyperplasia Support Association
1302 County Rd 4
Wrenshall, MN 55797
(218) 384-3863
2,3,9

ADRENOCORTICOTROPIC HORMONE DEFICIENCY

See: Adrenal Disorders; Pituitary Disorders

KEY TO SERVICES

1. Periodical/newsletter
2. Informational materials
3. Networking/matching
4. Referrals to local resources
5. Local chapters
6. National conferences
7. National advocacy efforts
8. Fund research
9. Maintain research registry

BEST COPY AVAILABLE

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
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4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

ADRENOGENITAL SYNDROME

See: Adrenal Hyperplasia, Congenital

ADRENOLEUKODYSTROPHY

See: Leukodystrophy; Tay-Sachs Disease

ADRENOLEUKODYSTROPHY NEONATAL

See: Leukodystrophy; Tay-Sachs Disease

AGENESIS OF COMMISSURA MAGNA CEREBRI

See: Agenesis of the Corpus Callosum

AGENESIS OF THE CORPUS CALLOSUM

See also: Aicardi Syndrome

ACC Network
5749 Merrill Hall, Rm 18
University of Maine
Orono, ME 04469-5749
(207) 581-3119
(207) 866-2062
(207) 581-3120 (fax)
✉ um-acc@maine.maine.edu
1,2,3

AGYRIA

See: Lissencephaly

AICARDI SYNDROME

See also: Agenesis of the Corpus Callosum; Epilepsy; Visual Impairments

Aicardi Syndrome Awareness and Support Group
79 Delavan Ave
Toronto, ON CAN M5P 1T2
(416) 481-4095
2,3,4,7,9

Aicardi Syndrome Newsletter
5115 Troy Urbana Rd
Casstown, OH 45312
(513) 339-6033 (voice/fax)
✉ asneditor@aol.com
1,2,3,4,6,7,8,9

AIDS

CDC National AIDS Hotline
American Society Health Assn
PO Box 13827
Research Triangle Park, NC 27709
(800) 342-2437
(800) 344-7432 (Spanish)
(800) 243-7889 (TTY)
(919) 361-4855 (fax)
2,4; materials in many languages

National Pediatric HIV Resource Center
15 S 9th St
Newark, NJ 07107
(800) 362-0071
(201) 268-8251
(201) 485-2752 (fax)
1,2,3,6,7; school nurse educational program

ALAGILLE SYNDROME

See also: Heart Disorders; Liver Disorders

Alagille Syndrome Alliance
10630 SW Garden Park Pl
Tigard, OR 97223
(503) 639-6217
1,2,3,9

ALANINURIA

See: Lactic Acidosis; Acidemia, Organic

ALBINISM & HYPOPIGMENTATION

See also: Visual Impairments

National Organization for Albinism and Hypopigmentation
1530 Locust St. # 29
Philadelphia, PA 19102
(800) 473-2310
✉ noah@albinism.org
http://www.albinism.org
1,2,5,6,7,9; Spanish materials

ALBRIGHT SYNDROME

See: McCune-Albright Syndrome

ALGONEURODYSTROPHY

See: Reflex Sympathetic Dystrophy Syndrome

ALLERGY

See: Asthma & Allergy; Food Allergy; Latex Allergy

ALLERGY, FOOD

See: Food Allergy

ALLERGY, LATEX

See: Latex Allergy

ALOPECIA AREATA

National Alopecia Areata Foundation
710 C Street, Ste 11
San Rafael, CA 94901
(415) 456-4644
(415) 456-4274 (fax)
✉ 74301.1642@compuserve.com
1,2,3,4,5,6,7,8,9; Spanish materials

ALOPECIA UNIVERSALA-ONYCHODYSTROPHY-TOTAL VITILIGO

See: Ectodermal Dysplasias; Vitiligo

ALOPECIA-ANOSMIA-DEAFNESS-HYPOGONADISM

See: Ectodermal Dysplasias

ALOPECIA-ONYCHODYSPLASIA-HYPOHIDROSIS

See: Ectodermal Dysplasias

ALPHA-1-ANTITRYPSIN (AAT) DEFICIENCY

See also: Liver Disorders; Lung Disorders

Alpha-1 National Association
1829 Portland Ave
Minneapolis, MN 55404
(612) 871-1747
(612) 871-9441 (fax)
1,2,3,4,5,6,7,9

ALPHA-GALACTOSIDASE DEFICIENCY

See: Fabry Disease

ALPORT SYNDROME

See: Hearing Impairments; Kidney Diseases, Hereditary; Vision Impairments

ALSTROM SYNDROME

See also: Diabetes Mellitus; Hearing Impairments; Kidney Disorders; Retinitis Pigmentosa; Visual Impairments

Alstrom Syndrome Newsletter
1006 Howard Rd
Warminster, PA 18974
1,9

ALTERNATING HEMIPLEGIA

See: Hemiplegia, Alternating

AMELOCEREBRO-HYPHOHIDROTIC SYNDROME

See: Ectodermal Dysplasias

AMELOONYCHO-HYPHOHIDROTIC DYSPLASIA

See: Ectodermal Dysplasias

AMNIOTIC BANDS

See: Craniofacial Disorders

AMPUTATION

See also: Limb Disorders

American Amputee Foundation
PO Box 250218
Little Rock, AR 72225
(501) 666-2523
(501) 666-8367 (fax)
1,2,4,5,9

National Amputation Foundation
73 Church St
Malvern, NY 11565
(516) 887-3600
(516) 887-3667 (fax)
1,2,3,4,7,9

AMSTERDAM DWARF SYNDROME OF DE LANGE

See: Cornelia de Lange Syndrome

AMYLO-1, 6-GLUCOSIDASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

AMYLOPECTINOSIS

See: Glycogen Storage Diseases

AMYOPLASIA, CONGENITA

See: Arthrogryposis Multiplex Congenita

ANAL ATRESIA

See: Anorectal Malformations

ANAL STENOSIS

See: Anorectal Malformations

ANDERSEN DISEASE

See: Glycogen Storage Diseases

ANDERSON-FABRY DISEASE

See: Fabry Disease

ANDERSON-WARBURG SYNDROME

See: Norrie Disease

ANEMIA, APLASTIC

See also: Anemia, Fanconi; Bone Marrow Transplant

Aplastic Anemia Association of Canada
22 Aikenhead Rd
Etobicoke, ON CAN M9R 2Z3
(416) 235-0468
(519) 576-7400 (fax)
1,2,3,4,7,8; French materials

Aplastic Anemia Foundation of America
PO Box 22689
Baltimore, MD 21203
(800) 747-2820
1,2,3,4,5,6,7,8,9; Spanish materials

ANEMIA, AREGENERATIVE

See: Anemia, Aplastic

ANEMIA, COOLEY

See: Cooley Anemia

ANEMIA, ERYTHROBLASTOTIC

See: Cooley Anemia

ANEMIA, FANCONI

See also: Anemia, Aplastic; Heart Disorders; Kidney Disorders; Leukemia

Fanconi Anemia Research Fund/Support Group
1902 Jefferson, #2
Eugene, OR 97405
(503) 687-4658
(503) 687-0548 (fax)
✉ fafund@rio.com
1,2,3,6,8,9; Spanish materials

ANEMIA, HEMOLYTIC

See: Cooley Anemia

ANEMIA, HYPOPLASTIC

See: Anemia, Aplastic

ANEMIA, MEDITERRANEAN

See: Cooley Anemia

ANEMIA, REFRACTORY

See: Anemia, Aplastic

ANEMIA, TARGET CELL

See: Cooley Anemia

ANEMIA, TOXIC PARALYTIC

See: Anemia, Aplastic

ANGELMAN SYNDROME

See also: Epilepsy

Angelman Syndrome Foundation
PO Box 12437
Gainesville, FL 32604
(800) 432-6435
✉ rjbatman@aol.com
1,2,3,5,6,7,8,9; Internet mail list—subscribe by sending e-mail to: majordomo@tbag.osc.edu

Canadian Angelman Syndrome Society
PO Box 37
Priddis, AB CAN T0L 1W0
(403) 931-2415 (voice/fax)
1,2,3,5,6,9; French materials

ANGIO-OSTEOHYPERTROPHY SYNDROME

See: Klippel-Trenaunay Syndrome

ANGIOKERATOMA CORPORIS DIFFUSUM

See: Fabry Disease

ANGIOMA

See: Hemangioma; Vascular Malformations

ANGIOMATOSIS RETINA

See: Von Hippel-Lindau Syndrome

ANIRIDIA

See: Visual Impairments

ANKYLOSING SPONDYLITIS, JUVENILE

See: Arthritis

ANOPHTHALMIA

See also: Visual Impairments

International Children's Anophthalmia Network
Old York Rd
Philadelphia, PA 19141
(800) 580-4226
(215) 456-8722
(215) 456-2356 (fax)
1,2,3,4,6,9

ANORECTAL MALFORMATIONS

See also: Intestinal Pseudo-Obstruction Syndrome

Pull-Thru Network
1 Circle Rd
Darien, CT 06820
(203) 655-6288
(201) 891-5932
1,2,3,4

APECED SYNDROME

See: Ectodermal Dysplasias; Hypoparathyroidism

APERT SYNDROME

See also: Craniofacial Disorders

Apert Support and Information Network
1626 Redwood Ave
Redwood City, CA 94061
(415) 361-1095 (voice/fax)
1,3

Apert Syndrome Pen Pal Network
PO Box 115
Providence, RI 02901
(401) 421-9076
3,4

Apert Syndrome Support Group
8708 Kathy St
St Louis, MO 63126
(314) 965-3356
3,4,5

APHASIA, ACQUIRED

See also: Brain Injury; Stroke

National Aphasia Association
PO Box 1887
Murray Hill Station
New York, NY 10156-0611
(800) 922-4622
(212) 727-9126 (fax)
1,2,3,8,9; Spanish materials

APLASTIC ANEMIA

See: Anemia, Aplastic

APNEA, INFANTILE

See: Apnea, Sleep

APNEA, SLEEP

American Sleep Apnea Association
PO Box 66
Belmont, MA 02178
(617) 489-4441
1,2,5,7,8

APRAXIA

See also: Language Disorders; Learning Disabilities

National Organization for Apraxia and Dyspraxia
7675 Charter Oaks Dr
Pensacola, FL 32514
(904) 478-4895 (voice/fax)
(904) 494-1444 (TTY)
dyspraxia@aol.com
1,2,3,4,7,9

AQUEDUCTAL STENOSIS

See: Hydrocephalus

ARACHNODACTYLY

See: Marfan Syndrome

AREGENERATIVE ANEMIA

See: Anemia, Aplastic

ARGINASE DEFICIENCY

See: Urea Cycle Disorders

ARGININOSUCCINASE DEFICIENCY

See: Urea Cycle Disorders

ARGININOSUCCINIC ACID SYNTHETASE DEFICIENCY

See: Urea Cycle Disorders

ARGININOSUCCINIC ACIDURIA

See: Urea Cycle Disorders

ARHINENCEPHALY

See: Holoprosencephaly

ARNOLD-CHIARI MALFORMATION

See also: Spina Bifida; Syringomyelia

Arnold-Chiari Family Network
c/o Maureen & Kevin Walsh
67 Spring St
Weymouth, MA 02188
(617) 337-2368
2,3

ARTERIOHEPATIC DYSPLASIA

See: Alagille Syndrome

ARTERIOVENOUS MALFORMATIONS (AVMS)

See also: Epilepsy; Stroke; Vascular Malformations

AVM Support Group of Nevada
PO Box 1261
Fernley, NV 89408
(702) 575-5421
2,3,4

ARTHO-OPHTHALMOPATHY

See: Stickler Syndrome

ARTHRITIS

American Juvenile Arthritis Organization
1314 Spring St NW
Atlanta, GA 30309
(800) 283-7800
(404) 872-7100
(404) 872-0457 (fax)
1,2,4,7,8; Spanish materials

Arthritis Society
250 Bloor St, Ste 901
Toronto, ON CAN M4W 3P2
(800) 361-1112 (ON only)
(416) 967-1414
(416) 967-7171 (fax)
1,2,6,8

ARTHROCHALASIS MULTIPLEX CONGENITA

See: Ehlers-Danlos Syndrome

ARTHROGRYPOSIS MULTIPLEX CONGENITA

See also: Growth Disorders; Muscular Dystrophy

AVENUES: A National Support Group for Arthrogryposis Multiplex Congenita
PO Box 5192
Sonora, CA 95370
(209) 928-3688
avenues@sonnet.com
http://www.sonnet.com/avenues
1,2,3,4

CAST: Canadian Arthrogryposis Support Team
365 Fiddler's Green Rd S
Ancaster, ON CAN L9G 1X2
(905) 648-2007
cast@freenet.hamilton.on.ca
1,2,3,4,5

ASCENDING PARAYLSIS

See: Guillain-Barré Syndrome

ASPERGER SYNDROME

See: Autism

ASTHMA

See: Asthma & Allergy

ASTHMA & ALLERGY

See also: Food Allergy; Latex Allergy; Lung Diseases

Allergy/Asthma Information Association
30 Eglinton Ave W, Ste 750
Mississauga, ON CAN L5R 3E7
(905) 712-2242
(905) 712-2245 (fax)
1,2,4,5,6,7,9; French materials

Asthma and Allergy Foundation of America
1125 15th St NW, Ste 502
Washington, DC 20005
(800) 727-8462
(202) 466-7643
(202) 466-8940 (fax)
1,2,4,5,7,8; Spanish materials

Asthma Society of Canada
130 Bridgeland Ave, Ste 425
Toronto, ON CAN M6A 1Z4
(416) 787-4050
(416) 787-5807 (fax)
1,2,3,4,8

ATAXIA

See also: Ataxia Telangiectasia; Charcot-Marie-Tooth Disease; Friedreich Ataxia; Von Hippel-Lindau Syndrome

National Ataxia Foundation
750 Twelve Oaks Ctr
15500 Wayzata Blvd
Wayzata, MN 55391
(612) 473-7666
(612) 473-9289 (fax)
naf@mr.net
1,2,3,4,5,6,8

ATAXIA, FAMILIAL

See: Ataxia; Friedreich Ataxia

ATAXIA, FRIEDREICH

See: Ataxia; Friedreich Ataxia

ATAXIA, SPINOCEREBELLAR

See: Ataxia; Friedreich Ataxia

ATAXIA TELANGIECTASIA

See also: Ataxia; Autoimmune Disorders; Cancer; Immune Disorders; Leukemia

Ataxia Telangiectasia Children's Project
398 W Camino Gardens Blvd, Ste 104
Boca Raton, FL 33432
(800) 543-5728
(407) 395-2621
(407) 395-2640 (fax)
bradmargus@delphi.com
http://www.med.jhu.edu/ataxia/
2,3,4,5,6,8,9

ATAXIA WITH LACTIC ACIDOSIS II

See: Ataxia; Leigh Disease

ATRESIA

See: Microtia

ATRIAL SEPTAL DEFECTS

See: Heart Disorders

ATROPHIA BULBORUM HEREDITARIA

See: Norrie Disease

ATTENTION DEFICIT DISORDER

See also: Learning Disabilities

AD-IN: Attention Deficit Information Network
475 Hillside Ave
Needham, MA 02194
(617) 455-9895
2,3,4,5,6,9

CHADD—Canada
1376 Bank St, Ste 214
Ottawa, ON CAN K1H 7H3
(613) 731-1209
(613) 731-1014 (fax)
http://magi.com/~anthonyp/chadd.html
1,2,5,9

CHADD: Children and Adults with Attention Deficit Disorders
499 NW 70th Ave, Ste 101
Plantation, FL 33317
(800) 233-4050
(305) 587-3700
(305) 587-4599 (fax)
1,2,3,5,6,9; Spanish materials

Challenge
PO Box 488
W Newbury, MA 01985-0688
(800) 233-2322
(508) 462-0495 (voice/fax)
1,2,4; prescription drug discount program

National Attention Deficit Disorder
PO Box 972
Mentor, OH 44061
(800) 487-2282
(216) 255-0422 (fax)
1,2,3,4,6,7,9

AURICULO-OCULO-VERTEBRAL SYNDROME

See: Goldenhar Syndrome

AUTISM

See also: Autism and Sensory Impairments; Language Disorders

Autism Research Institute
4182 Adams Ave
San Diego, CA 92116
(619) 281-7165
(619) 563-6840 (fax)
1,2,4,9

Autism Society of America
7910 Woodmont Ave, Ste 650
Bethesda, MD 20814
(800) 328-8476
(301) 657-0881
(301) 657-0869 (fax)
1,2,4,5,6,7,8; Spanish/French/Vietnamese/Chinese materials

Autism Society of Canada
129 Yorkville Ave, #202
Toronto, ON CAN M5R 1C4
(416) 922-0302 (Voice/fax)
(416) 922-1032 (fax)
1,2,4,5,7; French materials

Center for Study of Autism
9725 SW Beaverton-Hillsdale Hwy, Ste 230
Beaverton, OR 97005
(503) 692-3104 (voice/fax)
2,6

Learning Together
149 E Cortner St
Hanford, CA 93230
1,3

More Advanced Autistic People
PO Box 524
Crown Point, IN 46307
(219) 662-1311
(219) 662-0638 (fax)
1,2,4,6

National Autism Hotline/Autism Services Center
605 Ninth St
Prichard Bldg PO Box 507
Huntington, WV 25710-0507
(304) 525-8014
(304) 525-8026 (fax)
1,2,3,4,7; Spanish/Italian/French materials

AUTISM AND SENSORY IMPAIRMENTS

See also: Hearing Impairments; Language Disorders; Visual Impairments

The Autism Network for Hearing & Visually Impaired Persons
c/o Dolores and Alan Bartel
7510 Oceanfront Ave
Virginia Beach, VA 23451
(804) 428-9036
(804) 428-0019 (fax)
3,4,7,9

AUTOIMMUNE DISORDERS

See also: Immune Disorders; Vitiligo

American Autoimmune Related Diseases Association
Michigan National Bank Bldg
15475 Gratiot Ave
Detroit, MI 48205
(313) 371-8600
1,2,4,8

AVM

See: Arteriovenous Malformations (AVMs)

B12 METABOLISM; INBORN ERROR OF

See: Cobalamin (B12) Deficiency

BAISCH SYNDROME

See: Ectodermal Dysplasias

BALANCE DISORDERS & DIZZINESS

See also: Vestibular Disorders

EAR Foundation
1817 Patterson St
Nashville, TN 37203-2110
(800) 545-4327 (V/TTY)
(615) 329-7807
(615) 329-7935 (fax)
theearfd@aol.com
1,2,3,4,5

BARDET-BIEDL SYNDROME

See: Laurence-Moon-Bardet-Biedl Syndrome

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

BATTEN DISEASE

See also: Tay-Sachs Disease

Batten Disease Support and Research Association, Canadian Chapter
c/o Bev Maxim
17 Bell St
Regina, SK CAN S4S 4B7
(306) 789-9047
1,2,3,4,7,8,9

Batten's Disease Support and Research Association
2600 Parsons Ave
Columbus, OH 43207
(800) 448-4570
(614) 927-7551
1,2,3,4,5,6,8,9

Children's Brain Diseases Foundation
350 Parnassus Ave, Ste 900
San Francisco, CA 94117
(415) 565-6259
(415) 863-3452 (fax)
2,4,8

National Batten Disease Registry
1050 Forest Hill Rd
Staten Island, NY 10314-6399
(800) 952-9628
(718) 494-5201
(718) 698-3803 (fax)
2,3,4,5,6,8,9; genetic counseling, diagnostic testing

BATTEN-MAYOU SYNDROME

See: Batten Disease

BATTEN-SPIELMEYER-VOGT DISEASE

See: Batten Disease

BATTEN-VOGT SYNDROME

See: Batten Disease

BBB SYNDROME

See: Opitz Syndrome

BBBG SYNDROME

See: Opitz Syndrome

BECKER MUSCULAR DYSTROPHY

See: Muscular Dystrophy

BECKWITH-WIEDEMANN SYNDROME

Beckwith-Wiedemann Support Network
3206 Braeburn Cir
Ann Arbor, MI 48108
(800) 837-2976 (Parents only)
(313) 973-0263
(313) 973-9721 (fax)
a800bwsn@aol.com
1,2,3,6,9

BEDWETTING

See: Incontinence

BENIGN CONGENITAL HYPOTONIA

See: Spinal Muscular Atrophy

BEREAVEMENT SUPPORT

Center for Loss in Multiple Birth
PO Box 1064
Palmer, AK 99645-1064
(907) 746-6123
1,2,3,4

Compassionate Friends
PO Box 3696
Oak Brook, IL 60522-3696
(708) 990-0010
(708) 990-0246 (fax)
1,2,3,4,5,6; Spanish materials

Pen-Parents
PO Box 8738
Reno, NV 89507-8738
(702) 826-7332 (voice/fax)
fgck08a@prodigy.com
1,3,9

Pen-Parents of Canada
c/o Patty Lou Bryant
52548 RPO Coquitlam Ctr
Coquitlam, BC CAN V3B 7J4
(604) 469-1272
1,2,3,4,9

Pregnancy and Infant Loss Center
1421 East Wayzata Blvd, #30
Wayzata, MN 55391
(612) 473-9372
(612) 473-8978 (fax)
1,2,3,4,7,9; Spanish materials

BERGER DISEASE

See: IgA Nephropathy

BETA THALASSEMIA MAJOR

See: Cooley Anemia

BEUREN SYNDROME

See: Williams Syndrome

BILIARY ATRESIA

See also: Liver Disorders

Biliary Atresia & Liver Transplant Network
3835 Richmond Ave, Box 190
Staten Island, NY 10312-3828
(718) 987-6200 (voice/fax)
organtrans@aol.com
http://www.med.umich.edu/trans/transweb/support/bilitree.html
1,2,3,4,5,6,7,9; Spanish materials

BIOTINIDASE DEFICIENCY

See: Metabolic Disorders

BIRTHMARK

See: Nevi, Giant Congenital; Vascular Malformations

BLEEDING DISORDERS

See: Hemophilia

BLEPHAROPHIMOSIS, PTOSIS, EPICANTHUS INVERSUS SYNDROME (BPES)

See also: Craniofacial Disorders

Blepharophimosis, Ptosis, Epicanthus Inversus Support Group
c/o Lynne Schauble
SE 820 Meadow Vale Ln
Pullman, WA 99163
(509) 332-6628
1,2,3,7,9

BLEPHAROSPASM

See: Dystonia

BLINDNESS

See: Visual Impairments

BLOCH-SIEMENS-SULZBERGER SYNDROME

See: Incontinentia Pigmenti

BLOCH-SULZBERGER SYNDROME

See: Incontinentia Pigmenti

BLOOD VESSEL MALFORMATIONS

See: Hemorrhagic Telangiectasia; Hereditary; Vascular Malformations

BLOOM SYNDROME

See also: Cancer; Immune Disorders; Growth Disorders; Short Stature

Bloom Syndrome Registry
Laboratory of Human Genetics
NY Blood Ctr
310 E - 67th St
New York, NY 10021
(212) 570-3075
(212) 570-3195 (fax)
3,8,9

BONE MARROW TRANSPLANT

See also: Cancer

BMT Newsletter
1985 Spruce Ave
Highland Park, IL 60035
(708) 831-1913
(708) 831-1943 (fax)
1,2,3,4; legal referral for insurance problems

BONE TUMOR-EPIDERMOID CYST-POLYPOSIS

See: Peutz-Jeghers Syndrome; Polyposis

BONNEVIE-ULRICH SYNDROME

See: Turner Syndrome

BOOK SYNDROME

See: Ectodermal Dysplasias

BOURNEVILLE PRINGLE SYNDROME

See: Tuberous Sclerosis

BOWEL DYSFUNCTION

International Foundation for Bowel Dysfunction
PO Box 53217
Milwaukee, WI 17864
(414) 241-9479
(414) 241-9485 (fax)
ifbd@aol.com
1,2,4,5,6,7,8,9

BRACHIAL PLEXUS INJURY

See: Erb Palsy

BRACHMANN-DE LANGE SYNDROME

See: Cornelia de Lange Syndrome

BRAIN INJURY

See also: Aphasia, Acquired

Brain Injury Association
1776 Massachusetts Ave NW, Ste 100
Washington, DC 20036-1904
(800) 444-6443 (family helpline)
(202) 296-6443
(202) 296-8850 (fax)
1,2,4,5,6,7; Spanish materials

BRAIN STEM MALFORMATIONS

See: Arnold-Chiari Malformation; Joubert Syndrome; Syringomyelia

BRAIN TUMORS

See also: Acoustic Neuroma; Brain Injury; Cancer; Epilepsy; Von Hippel-Lindau Syndrome

American Brain Tumor Association
2720 River Rd, Ste 146
Des Plaines, IL 60018
(800) 886-2282
(847) 827-9910
(847) 827-9918 (fax)
abta@aol.com
http://neurosurgery.mgh.harvard.edu/ABTA/
1,2,3,4,6,7,8; Spanish materials

Brain Tumor Foundation for Children
2231 Perimeter Pk Dr, Ste 9
Atlanta, GA 30341
(770) 458-5554
(770) 458-5467 (fax)
1,2,3,4,7,8

Brain Tumor Foundation of Canada
111 Waterloo St, Ste 201
London, ON CAN N6B 2M4
(519) 642-7755
(519) 642-7192 (fax)
http://oncolink.upenn.edu/disease/brain/btfc/btfcped.html
1,2,6; French materials

Brain Tumor Society
60 Birmingham Pkwy
Boston, MA 02135-1116
(800) 770-8287
(617) 783-0340
(617) 783-9712 (fax)
1,2,3,4,6,7,8

Children's Brain Tumor Foundation
35 Alpine Ln
Chappaqua, NY 10514
(914) 238-1656
(914) 238-6024 (fax)
1,2,8

National Brain Tumor Foundation
c/o Michael McKechnie
785 Market St, Ste 1600
San Francisco, CA 94102
(800) 934-2873 (info line)
(415) 284-0208
(415) 284-0209 (fax)
satf39b@prodigy.com
1,2,3,4,5,6,8,9

BRANCHED CHAIN KETONURIA

See: Maple Syrup Urine Disease

BRANCHER DEFICIENCY

See: Glycogen Storage Diseases

BRANCHIO-OTO-RENAL SYNDROME

See: Craniofacial Disorders; Hearing Impairments; Kidney Disorders

BRITTLE BONE DISEASE

See: Osteogenesis Imperfecta

BROAD THUMB-HALLUX SYNDROME

See: Rubinstein-Taybi Syndrome

Three-year-old **Amber Luce** is never happier than during visits to the home of her favorite aunt and uncle. Amber, who has lissencephaly, spherocytosis and a seizure disorder, lives in Buffalo, Minnesota with her parents, Tony and Gwen. Gwen is happy to report that "it has been over two months since Amber's last seizure."

BURKE SYNDROME
See: Shwachman Syndrome

BURNS

Phoenix Society for Burn Survivors
11 Rust Hill Rd
Levittown, PA 19056
(800) 888-2876
(215) 946-2876
(215) 946-4788 (fax)
1,2,3,4,5,6,7,8,9

CALLOSAL AGENESIS
See: Agenesis of the Corpus Callosum; Aicardi Syndrome

CAMARENA SYNDROME
See: Ectodermal Dysplasias

CAMPTOMELIC SYNDROME
See: Growth Disorders; Short Stature

CANAVAN DISEASE
See: Leukodystrophy; Tay-Sachs Disease

CANCER
See also: Bone Marrow Transplant; Brain Tumors; Leukemia; Polyposis

American Cancer Society
1599 Clifton Rd NE
Atlanta, GA 30329-4251
(800) 227-2345
(404) 320-3333
(404) 329-5787 (fax)
2,6,8

Canadian Cancer Society
10 Alcorn Ave, Ste 200
Toronto, ON CAN M4V 3B1
(416) 961-7223
(416) 961-4189 (fax)
1,2,3,4,5,7,8; French materials

Candlelighters Childhood Cancer Foundation
7910 Woodmont Ave, Ste 460
Bethesda, MD 20814
(800) 366-2223
(301) 718-2686 (fax)
75717.3513@compuserve.com
1,2,3,4,5,7; Survivors of Childhood Cancer program, speakers bureau

Candlelighters Childhood Cancer Foundation Canada
55 Eglinton Ave E, Ste 401
Toronto, ON CAN M4P 1G8
(800) 363-1062 (Canada only)
(416) 489-6440
(416) 489-9812
1,2,3,4,5,6,7; French/Polish/German materials

CANCER; BRAIN
See: Brain Tumors

CANCER; GASTROINTESTINAL
See: Peutz-Jeghers Syndrome; Polyposis

CARBAMYL PHOSPHATE SYNTHETASE (CPS) DEFICIENCY
See: Urea Cycle Disorders

CARDIAC DISORDERS
See: Heart Disorders

CARDIO-FACIO-CUTANEOUS SYNDROME
See also: Heart Disorders; Ichthyosis

CFC Support Network
157 Alder Ave
Egg Harbor Twp, NJ 08234-9304
(609) 646-5606
1,3,9

CAREY SYNDROME
See: Ectodermal Dysplasias

CARNITINE DEFICIENCY SYNDROMES
See also: Acidemia, Organic; Fatty Oxidation Disorder; Muscular Dystrophy

Assistance for Babies and Children with Carnitine Deficiency
1010 Jorie Blvd, Ste 234
Oak Brook, IL 60521
(800) 554-2223
(703) 827-8771
(703) 827-0783 (fax)
ballard1@ix.netcom.com
1,2,3,4,7,8,9

CARNITINE PALMITYL TRANSFERASE DEFICIENCY
See: Acidemia, Organic; Fatty Oxidation Disorder; Carnitine Deficiency Syndromes; Muscular Dystrophy

CARPENTER SYNDROME
See also: Craniofacial Disorders

Carpenter Syndrome Network
c/o Cathy Sponsler
26661 Bear Valley Rd
Tehachapi, CA 93561
(805) 821-1313
carpenter.syndrome@php.com
1,3,4,6

CARTILAGE-HAIR HYPOPLASIA
See: Dwarfism; Growth Disorders; Short Stature

CARTILAGNOUS ENCHONDROSES, MULTIPLE
See: Ollier Disease

CAT'S CRY SYNDROME
See: Cri Du Chat Syndrome

CAUSALGIA SYNDROME
See: Reflex Sympathetic Dystrophy Syndrome

CELIAC DISEASE
See also: Celiac Sprue; Gluten Intolerance

Canadian Celiac Association
65 19B Mississauga Rd
Mississauga, ON CAN L5N 1A6
(905) 567-7195
(905) 567-0710 (fax)
1,2,3,4,5,6,7,8,9; French materials

Celiac Disease Foundation
13251 Ventura Blvd, #3
Studio City
Los Angeles, CA 91604-1838
(818) 990-2354
(818) 990-2379 (fax)
1,2,3,4

CELIAC SPRUE
See also: Celiac Disease; Gluten Intolerance

American Celiac Society
58 Musano Ct
West Orange, NJ 07052
(201) 325-8837
(201) 669-8808 (fax)
bentleac@umdnj.edu
1,2,3,4,5,6,7,9; speakers bureau

Celiac Sprue Association
PO Box 31700
Omaha, NE 68131-0700
(402) 558-0600
(402) 558-1347 (fax)
1,2,4,5,6,7,8

CENTRAL CORE DISEASE
See: Muscular Dystrophy

CENTRAL HYPOVENTILATION SYNDROME, CONGENITAL
See also: Apnea, Sleep; Intestinal Pseudo-Obstruction Syndrome; Ventilator Use

Congenital Central Hypoventilation Syndrome Parent Network
71 Maple St
Oneonta, NY 13820
vanderlaanm@hartwick.edu
1,2,3,4,6,9

CEREBELLAR HYPOPLASIA
See: Joubert Syndrome

CEREBELLAR VERMIS APLASIA/HYPOPLASIA
See: Joubert Syndrome

CEREBELLO-OCULOCUTANEOUS TELANGIECTASIA
See: Ataxia Telangiectasia

CEREBELLORETINAL HEMANGIOBLASTOMATOSIS
See: Von Hippel-Lindau Syndrome

CEREBRAL GIGANTISM
See: Sotos Syndrome

CEREBRAL PALSY

Ontario Federation for Cerebral Palsy
1630 Lawrence Ave W, Ste 104
Toronto, ON CAN M6L 1C5
(416) 244-8003
(416) 244-6543 (fax)
1,2,3,4,5,6,7,8,9

United Cerebral Palsy Associations
1660 L St NW, Ste 700
Washington, DC 20036-5602
(800) 872-5827
(202) 776-0406 (V/TTY)
(202) 776-0414 (fax)
ucpainc@aol.com
1,2,4,5,6,7; Spanish materials, provides direct services through 158 affiliate programs

CEREBROOCULORENAL DYSTROPHY
See: Lowe Syndrome

CEREBROSIDE LIPIDOSIS
See: Gaucher Disease

CEREBROTENDINOUS XANTHOMATOSIS
See: Leukodystrophy; Tay-Sachs Disease

CHALASODERMIA
See: Connective Tissue Disorders

CHANARIN-DORFMAN SYNDROME
See: Ichthyosis

CHANDS ASSOCIATION
See: Ectodermal Dysplasias

CHARCOT-MARIE-TOOTH DISEASE
See also: Ataxia; Muscular Dystrophy; Myelin Disorders

Charcot-Marie-Tooth Association
601 Upland Ave
Upland, PA 19015
(800) 606-2682
(610) 499-7486
(610) 499-7487(fax)
1,2,4,6,8,9; Spanish materials

Charcot-Marie-Tooth International
1 Springbank Dr
St Catharines, ON CAN L2S 2K1
(905) 687-3630
(905) 687-8753 (fax)
1,2,3,4,8,9; scholarship program

CHARGE ASSOCIATION
See also: DiGeorge Syndrome; Heart Disorders; Hearing Impairments; Velo-Cardio-Facial Syndrome; VATERL Association; Visual Impairments

CHARGE Syndrome Foundation
2004 Parkade Blvd
Columbia, MO 65202-3121
(800) 442-7604
(573) 499-4694
(573) 874-1535 (fax)
mnorbury@mail.com.missouri.edu
1,2,3,4,5,6,9; Spanish materials

CHEMKE SYNDROME
See: Hydrocephalus; Lissencephaly

CHIARI MALFORMATION
See: Arnold-Chiari Malformation

CHILD SYNDROME
See: Ichthyosis

CHOLESTATIS WITH PERIPHERAL PULMONARY STENOSIS
See: Alagille Syndrome

CHOLESTERYL ESTER STORAGE DISEASE
See: Tay-Sachs Disease

CHONDRODYSPLASIA PUNCTATA
See: Growth Disorders; Ichthyosis

CHONDRODYSTROPHY, HYPERPLASTIC
See: Dwarfism, Metatrophic

CHORIONIC VILLUS SAMPLING, RELATED DISABILITIES
See also: Limb Disorders

CVS Parent Network Support Group
15830 Orland Brook Dr
Orland Park, IL 60462
(708) 349-8984
1,2,4

CHOROIDEREMIA
See: Macular Diseases; Retinitis Pigmentosa; Visual Impairments

CHRIST-SIEMENS-TOURAINE SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias

CHROMOSOME 3, MONOSOMY 3P2
See: Chromosome Deletions

CHROMOSOME 4 RING
See: Chromosome Deletions; Wolf-Hirschhorn Syndrome

CHROMOSOME 4P-
See: Wolf-Hirschhorn Syndrome

CHROMOSOME 5P-
See: Cri Du Chat Syndrome

CHROMOSOME 6 DISORDERS

Spotlight 6
c/o Valerie Wiggins
568 Jamestown Ct
Edgewood, MD 21040
(410) 6713183
1,3,9

BEST COPY AVAILABLE

CHROMOSOME 8P DISORDERS

8p Duplication Support Group
Genetics Ctr
Children's Medical Ctr
1 Children's Plaza
Dayton, OH 45404
(513) 226-8408
(513) 463-5325 (fax)
3

CHROMOSOME 9 DISORDERS

Support Group for 9p-
c/o Beverly Udell
675 N Round Table Dr
Las Vegas, NV 89110
(702) 453-0788
1,2,3,8,9

Support Group for Monosomy 9p
43304 Kipton Nickle Plate Rd
La Grange, OH 44050
(216) 775-4255
1,2,3,8,9

Trisomy 9 International Parent Support
Children's Hospital of Michigan
3901 Beaubien Blvd
Detroit, MI 48201-2196
(313) 745-4513
(313) 745-4827 (fax)
1,3,9

CHROMOSOME 9 RING

See: Chromosome 9 Disorders; Chromosome Deletions; Craniofacial Disorders

CHROMOSOME 11Q DISORDERS

See also: Craniofacial Disorders; Heart Disorders; Visual Impairments

11q Research and Resource Group
6123a Duncan Rd
Petersburgh, VA 23803
(804) 863-2114
2,3,6,9

CHROMOSOME 13 & 18 DISORDERS

See also: Chromosome 18 Disorders

SOFT Canada: Support Organization for Trisomy 18, 13 and Related Disorders
760 Brant St, Ste 420
Burlington, ON CAN L7R 4B8
(800) 668-0898 (Canada only)
(905) 632-7755
(905) 632-5997 (fax)
1,2,3,4,5,6,8,9; also covers other rare trisomy disorders

SOFT: Support Organization for Trisomy 18, 13 and Related Disorders
c/o Barb Van Herrewegne
2982 S Union St
Rochester, NY 14624
(800) 716-7638
(716) 594-4621 (voice/fax)
1,2,3,5,6,9; also covers other rare trisomy disorders

CHROMOSOME 15 DISORDERS

IDEAS: Inverted Duplication Exchange, Advocacy and Support
c/o Donna Bennett
RD #1, Box 260B
Thomasville, PA 17364-9768
(717) 225-5229
(610) 891-2313
1,2,3

CHROMOSOME 17P-

See: Smith-Magenis Syndrome

CHROMOSOME 18 DISORDERS

See also: Chromosome 13 & 18 Disorders

Chromosome 18 Registry & Research Society
6302 Fox Head
San Antonio, TX 78247
(210) 657-4968 (voice/fax)
cody@uthscsa.edu
1,2,3,6,9

CHROMOSOME 21 RING

See: Chromosome Deletions

CHROMOSOME 22 RING

See: Chromosome Deletions

CHROMOSOME 45,X

See: Turner Syndrome

CHROMOSOME 45,X/46,XX

See: Turner Syndrome

CHROMOSOME 46XY/47,XXY

See: Klinefelter Syndrome

CHROMOSOME 47,XXY

See: Klinefelter Syndrome

CHROMOSOME 47,XYY

See: Klinefelter Syndrome

CHROMOSOME 48,XXXY

See: Klinefelter Syndrome

CHROMOSOME 48,XXYY

See: Klinefelter Syndrome

CHROMOSOME 49,XXXXY

See: Klinefelter Syndrome

CHROMOSOME DELETIONS

Chromosome Deletion Outreach
PO Box 280
Driggs, ID 83422
(208) 354-8550
(208) 456-2768 (fax)
1,3,4; also deals with chromosome translocations

CHROMOSOME INVERSIONS

National Center on Chromosome Inversions
1029 Johnson St
Des Moines, IA 50315
(515) 287-6798 (voice/fax)
3,4,9

CHROMOSOME TRANSLOCATIONS

See: Chromosome Deletions

CHROMOSOME TRISOMY DISORDERS

See: Chromosome 13 & 18 Disorders

CHRONIC ENCEPHALITIS & EPILEPSY

See: Rasmussen Syndrome

CHRONIC FATIGUE SYNDROME

CIFDS Association of America
PO Box 220398
Charlotte, NC 28222-0398
(800) 442-3437
(704) 365-9755 (fax)
cfids@vnet.net
1,2,3,6,7,8

CHRONIC INFLAMMATORY DEMYELINATING POLYRADICULONEUROPATHY

See: Guillain-Barre Syndrome

CHRONIC LOCALIZED ENCEPHALITIS

See: Rasmussen Syndrome

CITRULLINEMIA

See: Urea Cycle Disorders

CLEFT PALATE

See also: Craniofacial Disorders

Cleft Palate Foundation
1218 Grandview Ave
Pittsburgh, PA 15211
(800) 242-5338
(412) 481-1376
(412) 481-0847 (fax)
cleftline@aol.com
2,3,4,6,7,8; Spanish materials

CMV, CONGENITAL

See: Cytomegalovirus (CMV), Congenital

COBALAMIN (B12) DEFIENCY

See also: Metabolic Disorders

Cobalamin Network
PO Box 174
Thetford Center, VT 05075-0174
(802) 785-4029
3

COCKAYNE SYNDROME

See also: Growth Disorders; Xeroderma Pigmentosum

Share and Care Cockayne Syndrome Network
c/o Teresa Wall
PO Box 552
Stanleytown, VA 24168
(540) 629-2369
(540) 647-3739 (fax)
1,2,3,6,9; Spanish/Japanese materials

COFFIN-LOWRY SYNDROME

Coffin-Lowry Syndrome Foundation
13827 196th Ave SE
Renton, WA 98059
(206) 204-9176
74252.3077@compuserve.com
1,2,3,9

COLITIS

See: Crohn Disease & Colitis

COLOBOMA

See: Visual Impairments

COMPLEX REGIONAL PAIN SYNDROME

See: Reflex Sympathetic Dystrophy Syndrome

CONGENITAL ADRENAL HYPERPLASIA (CAH)

See: Adrenal Hyperplasia, Congenital

CONGENITAL LIPOID HYPERPLASIA

See: Adrenal Hyperplasia, Congenital

CONGENITAL SENSORY NEUROPATHY WITH ANHIDROSIS

See: Familial Dysautonomia

CONNECTIVE TISSUE DISORDERS

See also: Ehlers-Danlos Syndrome; Epidermolysis Bullosa, Dystrophic; Marfan Syndrome; Pseudoxanthoma Elasticum (PXE)

Coalition for Heritable Disorders of Connective Tissue
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712
(516) 883-8712 (fax)
1,2,3,4,6,7,8

CONRADI-HÜNERMANN SYNDROME

See: Growth Disorders; Ichthyosis

COOLEY ANEMIA

Cooley's Anemia Foundation
12909 26th Ave
Flushing, NY 11354
(800) 552-7222
(718) 321-2873
(718) 321-3340 (fax)
1,2,3,4,5,6,7,8,9; Italian/Greek/Chinese materials

Thalassemia Action Group
12909 26th Ave, Ste 203
Flushing, NY 11354
(800) 522-7222
(718) 321-2873
(718) 321-3340 (fax)
1,2,4,6,8

Thalassemia Foundation
32 Fern Ave
Weston, Ontario CAn M9N 1M2
(416) 242-8425
1,2,3,4,5,6,7,8,9

COPPER DEFICIENCY, X-LINKED

See: Menkes Disease

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

COPPER MALABSORPTION, X-LINKED

See: Menkes Disease

CORI DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

CORNELIA DE LANGE SYNDROME

Cornelia de Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355
(800) 753-2357
(860) 693-0159
(860) 693-6819 (fax)
1,2,3,4,6,9; professional network

CORPUS CALLOSUM DISORDERS

See: Agenesis of the Corpus Callosum; Aicardi Syndrome

COX DEFICIENCY

See: Leigh Disease

CRANIOCARPOTARSAL DYSTROPHY

See: Freeman-Sheldon Syndrome

CRANIOFACIAL DISORDERS

See also: Apert Syndrome; Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES); Carpenter Syndrome; Chromosome 11q Disorders; Cleft Palate; Crouzon Disease; Dubowitz Syndrome; Freeman-Sheldon Syndrome; Goldenhar Syndrome; Hemangioma; Holoprosencephaly; Microtia; Moebius Syndrome; Nager & Miller Syndromes; Nevi, Giant Congenital; Robinow Syndrome; Rubinstein-Taybi Syndrome; Stickler Syndrome; Sturge-Weber Syndrome; Treacher Collins Syndrome; Velo-Cardio-Facial Syndrome

AboutFace–Canada
99 Crowns Ln, 4th Fl
Toronto, ON CAN M5R 3P4
(800) 665-3223
(416) 944-3223
(416) 944-2488 (fax)
1,2,3,4,5,6

AboutFace–USA
PO Box 93
Limekiln, PA 19535
(800) 225-3223
(610) 689-4476
(610) 689-4479 (fax)
✉ abtface@aol.com
1,2,3,4,5,6,7

Children's Craniofacial Association
9441 LBJ Freeway, Ste 115
Dallas, TX 75243
(800) 535-3643
(214) 994-9902
(214) 994-9831 (fax)
1,2,3,4,5,6,7; Spanish materials, financial assistance for treatment-related expenses, annual family retreat

Craniofacial Foundation of America
c/o Terri Farmer
975 E Third St
Chattanooga, TN 37403
(615) 778-9192
(423) 778-9011 (fax)
1,2,3,4,5,7

FACES–National Association for the Craniofacially Handicapped
PO Box 11082
Chattanooga, TN 37401
(800) 332-2373
(423) 267-3124 (fax)
1,2,3,4,7,9; financial assistance for medical-related travel

Forward Face: The Charity for Children with Craniofacial Conditions
Inst of Reconstructive Plastic Surgery
317 34th St, Rm 901A
New York, NY 10016
(800) 393-3223
(212) 684-5860
(212) 684-5864 (fax)
1,2,3,4,9; teen/young adult group

Let's Face It
PO Box 29972
Bellingham, WA 98228-1972
(360) 676-7325
1,2,3,5,7; publishes annual resource guide

National Foundation for Facial Reconstruction
317 E 34th St, Rm 901
New York, NY 10016
(212) 263-6656
(212) 263-7534 (fax)
1,3,4,8,9

CRANIOFACIAL DYSOTOSIS

See: Crouzon Disease

CRANIOSYNOSTOSIS

See: Craniofacial Disorders

CRI DU CHAT SYNDROME

5p- Society
11609 Oakmont
Overland Park, KS 66210
(913) 469-8900
✉ fivepminus@aol.com
1,2,3,6,7,8,9

CRIB DEATH

See: Sudden Infant Death Syndrome (SIDS)

CROHN DISEASE & COLITIS

CCFA: Crohn's & Colitis Foundation of America
386 Park Ave S, 17th Fl
New York, NY 10016-8804
(800) 932-2423
(212) 685-3440
(212) 779-4098 (fax)
✉ mhda37b@prodigy.com
1,2,3,4,5,6,7,8,9; Spanish materials

Crohn's and Colitis Foundation of Canada
21 St Clair Ave E, Ste 301
Toronto, ON CAN M4T 1L9
(416) 920-5035
(416) 929-0364 (fax)
1,2,5,6,8; French materials

Pediatric Crohn's & Colitis Association
Box 188
Newton, MA 02168
(617) 290-0902 (voice/fax)
1,2,3,4,6,7,8

CROUZON DISEASE

See also: Craniofacial Disorders; Hearing Impairments; Visual Impairments

Crouzon's/Meniere's Parent Support Network
c/o Kathleen Handsaker
PO Box 12791
Prescott, AZ 86304-2791
(602) 445-1743
3,4

CURLY HAIR-ANKYLOBLEPHARON-NAIL DYSPLASIA (CHANDS)

See: Ectodermal Dysplasias

CUSHING SYNDROME

See: Adrenal Disorders

CUTANEOUS MASTOCYTOSIS

See: Mastocytosis

CUTIS HYPERELASTICA

See: Ehlers-Danlos Syndrome

CUTIS LAXA

See: Connective Tissue Disorders

CVS-RELATED DISABILITIES

See: Chorionic Villus Sampling, Related Disabilities

CYCLIC VOMITING SYNDROME

Cyclic Vomiting Syndrome Association
13180 Caroline Ct
Elm Grove, WI 53122
(414) 784-6842
(414) 7821-5494 (fax)
✉ kadams@post.its.mcw.edu
1,2,3,4,6,8,9

CYSTIC FIBROSIS

Canadian Cystic Fibrosis Foundation
2221 Yonge St, Ste 601
Toronto, ON CAN M4S 2B4
(800) 378-2233 (Canada only)
(416) 485-9149
(416) 485-0960 (fax)
✉ 76145.2325@compuserve.com
http://www.ccff.ca/~cfwww/index.html
1,2,3,4,5,6,7,8,9; French materials

Cystic Fibrosis Foundation
6931 Arlington Rd
Bethesda, MD 20814
(800) 344-4823
(301) 951-4422
(301) 951-6378 (fax)
1,2,5,6,8,9

CYSTINOSIS

See also: Kidney Disorders

Cystinosis Foundation
1212 Broadway, Ste 830
Oakland, CA 94612
(800) 392-8458
(510) 834-3741 (fax)
1,2,3,4,6,7,8,9; Italian materials

CYSTINURIA

See also: Kidney Disorders

Cystinuria Support Network
22814 NE 21st Pl
Redmond, WA 98053
(206) 868-2996 (voice/fax)
✉ cystinuria@aol.com
1,3

CYTOCHROME C OXIDASE (COX) DEFICIENCY

See: Leigh Disease; Mitochondrial Disorders

CYTOMEGALOVIRUS (CMV), CONGENITAL

National CMV Registry
c/o Gail Demmler, MD
Texas Children's Hospital
6621 Fannin St, MC 3-2371
Houston, TX 77030-2399
(713) 770-4330
(713) 770-4347 (fax)
✉ cmv@bcm.tmc.edu
1,2,3,4,8,9

DANDY-WALKER SYNDROME

Dandy-Walker Syndrome Network
5030 142nd Path W
Apple Valley, MN 55124
(612) 423-4008
3,4

DARIER DISEASE

See: Ichthyosis

DE BARSEY SYNDROME

See: Connective Tissue Disorders

DE BARSEY-MOENS-DIERCKS SYNDROME

See: Connective Tissue Disorders

DE MORSIER SYNDROME

See: Septo-Optic Dysplasia

DEAF-BLIND

See also: Hearing Impairments; Visual Impairments

American Association of the Deaf-Blind
814 Thayer Ave, Ste 302
Silver Spring, MD 20910
(301) 588-6545 (TTY only)
(301) 588-8705 (fax)
1,4,6

Canadian Deaf-Blind and Rubella Association
747 2nd Ave E, Ste 4
Owen Sound, ON CAN N4K 2G9
(519) 372-1333
(519) 372-1334 (fax)
1,2,3,4,5,6,7,9; French materials, camp, family retreats

DB-LINK: National Information Clearinghouse on Children Who are Deaf-Blind
345 N Monmouth Ave
Monmouth, OR 97361
(800) 438-9376
(800) 854-7013 (TTY)
(503) 838-8150 (fax)
✉ lesliep@tsh.wosc.osshe.edu
1,2,4,6; Spanish materials

National Family Association for Deaf-Blind
111 Middle Neck Rd
Sands Point, NY 11050
(800) 255-0411, ext 275
(516) 944-8637 (TTY)
(516) 944-7302 (fax)
1,2,3,4,5,6,7,9

DEAFNESS

See: Hearing Impairments

DEATH

See: Bereavement Support

DEBRANCHER ENZYME DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

DECARBOXYLICACIDURIA

See: Fatty Oxidation Disorder

DECEREBRATE DEMENTIA

See: Subacute Sclerosing Panencephalitis

DEJERINE SOTTAS DISEASE

See: Muscular Dystrophy

DEJERINE-LANDOUZY, MUSCULAR DYSTROPHY

See: Facio-Scapulo-Humeral Muscular Dystrophy

DELTA STORAGE POOL DISEASE

See: Hermansky-Pudlak Syndrome

DENTOOCULOCUTANEOUS SYNDROME

See: Ectodermal Dysplasias

DERMATITIS HERPETIFORMIS

See: Celiac Disease, Celiac Sprue, Gluten Intolerance

DERMATOCHALASIA

See: Connective Tissue Disorders

DERMATOLYSIS

See: Connective Tissue Disorders

DERMATOMEGALY

See: Connective Tissue Disorders

DERMATOMYOSITIS

See: Arthritis; Muscular Dystrophy; Myositis

DERMOODONTODYSPLASIA

See: Ectodermal Dysplasias

DERMOTRICHIC SYNDROME

See: Ectodermal Dysplasias

DEVELOPMENTAL DISABILITIES

See: Mental Retardation

DIABETES MELLITUS

See also: Kidney Disorders

American Diabetes Association
National Service Ctr
1660 Duke St
Alexandria, VA 22314
(800) 232-3472
(703) 549-1500
(703) 683-2890 (fax)
1,2,5,6,7,8

Canadian Diabetes Association
15 Toronto St, Ste 1001
Toronto, ON CAN M5C 2E3
(416) 363-3373
(416) 363-3393 (fax)
http://www.diabetes.ca
1,2,4,6,7,8; French materials

Juvenile Diabetes Foundation—Canada
89 Granton Dr
Richmond Hill, ON CAN L4B 2N5
(800) 668-0274 (Canada only)
(905) 889-4171
(905) 889-4209 (fax)
1,3,5,6,8,9

Juvenile Diabetes Foundation International
120 Wall St
New York, NY 10005
(800) 533-2873
(212) 785-9500
(212) 785-9595 (fax)
✉ jbroch@hdf.usa.com
1,2,3,4,5,6,7,8,9; Spanish materials

DIAPHYSEAL ACLASIS

See: Exostoses, Multiple Hereditary

DIGEORGE SYNDROME

See also: CHARGE Association; Heart Disorders; Hypoparathyroidism; Immune Disorders; Velo-Cardio-Facial Syndrome

Information and Support for DiGeorge and Shprintzen Syndrome Families
c/o Natalie Ward
27859 Lassen St
Castaic, CA 91384
(805) 294-3623
1,2,3,4,9

Dear Exceptional Parent Reader:

Flaghouse is honored to sponsor the Exceptional Parent 1996 Resource Guide. We strongly support the magazine's mission of providing practical information and emotional support.

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George Carmel

George Carmel, President
and the entire Flaghouse Team

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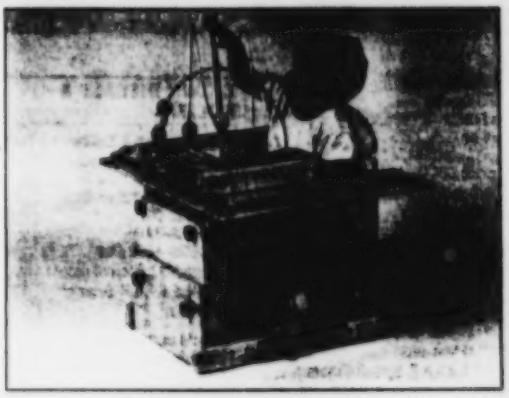


BOLSTER CHAIRS

Handsome furniture or physical therapy? These great chairs are both! Chair back and tray promote trunk extension while flat padded "bolster bench" combines comfort with stability and proper positioning. Relaxes muscle tone and enhances alignment of lower extremities. Includes pelvic strap and tray; mobile base and thoracic pads optional. Preschool and primary age sizes.

1128 Preschool Bolster Chair.	**$425.00 ea.**
5134 Mobile Base for Preschool Chair.	**$165.00 ea.**
8031 Thoracic Pads for Preschool Chair.	**$85.00 pr.**
1145 Primary Bolster Chair.	**$515.00 ea.**
7833 Mobile Base for Primary Chair.	**$185.00 ea.**
1133 Thoracic Pads for Primary Chair.	**$95.00 pr.**

BALL BATH

It's like being inside a bubble-gun machine full of brilliantly colored balls of fun. Beloved by all ages 9 months to six years. Choose bath with 1,000 balls for use by two or more children; 1500 size for use with just one. Air-walled tub inflates with pumps sold separately.

7731 Ball Bath 1000.	**$499.00 set**
7838 Ball Bath 1500.	**$625.00 set**
8011 Electric Inflator/Deflator.	**$49.95 ea.**
1141 Foot Pump.	**$22.95 ea.**

BEST COPY AVAILABLE

WHIRL-O-WHEEL

Indy 500 anyone? This sporty model sprints through 30" doorways, revolves 360° in place, and brakes with a forward body tilt. Entertaining, empowering, and practical too; promotes upper arm strength and manual dexterity.

7966 Children's Whirl-O-Wheel.	$229.95 ea.
7939 Adult's Whirl-O-Wheel. Includes leg extension.	$269.95 ea.
7935 Back Support. Fits all.	$71.50 ea.

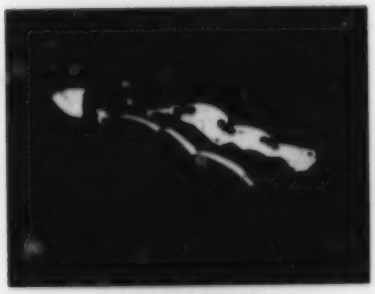
WAGON WALKER

Whee! Take tows for a ride and build walking skills and endurance at the same time. Handle adjusts to upright posture. The Wagon Walker is easily managed by children ages 1-4.

7732 Toddler Wagon Walker.	$143.00 ea.
6599 Preschool Wagon Walker.	$137.00 ea.

Flaghouse Favorites

These products are some of our customers' favorites—our SPECIAL POPULATIONS Catalog features more than 5,000 items for Therapy, Education and Fun!



SECTIONAL RAFT

Gently down to sea is how children float in this comfortable sectional raft that supports the entire body. Adjustable head support offers prone or supine option.

7491 Child's Sectional Raft.	$224.00 ea.
7694 Adult's Sectional Raft.	$254.50 ea.

ANIMAL MUSIC PUZZLE AND TOY

Old McDonald's farm was never this much fun. Cow, Cow, Piggy and Teddy are beautifully hand-painted wood pieces backed with 3" tall knobs. The completed puzzle plays happy music and activates the connected battery operated toy cow.

7818 Animal Music Puzzle and Toy Cow.	$89.00 ea.

NINE BUTTON SENSORY STIMULATION BOX

Engage your child's sense of wonder. You'll love watching your child experiment with nine different delights, from a gently blowing breeze to a harmonious tune.

8028 Sensory Stimulation Box.	$199.00 ea.

BOWLING RAMP

Now stationary players can enjoy the thrill of bowling. Ball rests on welded chrome steel frame. One gentle push and it's down the ramp, gaining speed, heading for a strike.

8026 Bowling Ramp.	$139.00 ea.

To order these items or to request your free 201 page catalog, call today.

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Email: info@flaghouse.com
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Suite 97634
Mount Vernon, NY 10550

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KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

DIGESTIVE DISORDERS

See: Celiac Disease; Celiac Sprue; Crohn Disease & Colitis; Gluten Intolerance; Intestinal Pseudo-Obstruction Syndrome; Ostomy

DIGESTIVE DYSMOTILITY

See: Intestinal Pseudo-Obstruction Syndrome

DIMORSIER SYNDROME

See: Growth Disorders

DOWN SYNDROME

Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710
(516) 221-4700
(516) 221-4311 (fax)
1,2,3,4,7,8,9; Spanish materials

Canadian Down Syndrome Society
811 14th St NW
Calgary, AB CAN T2N 2A4
(403) 270-8500
(403) 270-8291 (fax)
1,2,4,5,6,7,8; French materials

International Foundation for Genetic Research
500A Garden City Dr
Pittsburgh, PA 15146
(412) 823-6380
(412) 373-7713 (fax)
1,2,4,7,8

National Down Syndrome Congress
1605 Chantilly Dr, Ste 250
Atlanta, GA 30324
(800) 232-6372
(404) 633-1555
(404) 633-2817 (fax)
ndsc@charitiesusa.com
1,2,3,4,5,6,7

National Down Syndrome Society
666 Broadway, 8th Fl
New York, NY 10012-2317
(800) 221-4602
(212) 460-9330
(212) 979-2873 (fax)
1,2,4,5,6,7,8; Spanish materials

DUBOWITZ SYNDROME

See also: Craniofacial Disorders; Growth Disorders

Dubowitz Syndrome Parent Support Network
PO Box 173
Wheatland, IN 47597
(812) 886-0575
(812) 886-1128 (fax)
2,3,9

DUCHENNE MUSCULAR DYSTROPHY

See: Muscular Dystrophy

DWARFISM

See also: Dwarfism, Metatrophic; Growth Disorders; Short Stature

Billy Barty Foundation
929 W Olive Ave, Ste C
Burbank, CA 91506
(800) 891-4022
(818) 953-5410
(818) 953-7129 (fax)
1,4,7; emergency financial assistance, scholarships

DWARFISM, METATROPHIC

See also: Dwarfism; Growth Disorders; Short Stature

Metatrophic Dysplasia Dwarf Registry
3393 Geneva Dr
Santa Clara, CA 95051
(408) 244-6354
(408) 296-6317 (fax)
figone@netgate.net
2,3,4,9

DYGENESIS OF THE CORPUS CALLOSUM

See: Agenesis of the Corpus Callosum

DYSAUTONOMIA, FAMILIAL

See: Familial Dysautonomia

DYSKERATOSIS, CONGENITAL

See: Ectodermal Dysplasias

DYSLEXIA

See also: Attention Deficit Disorder; Language Disorders; Learning Disabilities

Dyslexia Research Institute
4745 Centerville Rd
Tallahassee, FL 32308
(904) 893-2216
(904) 893-2440 (fax)
2,4,7; teacher training, workshops

Orton Dyslexia Society
Chester Bldg, Ste 382
8600 La Salle Rd
Baltimore, MD 21286-2044
(800) 222-3123
(410) 296-0232
(410) 321-5069 (fax)
ods@pie.org
1,2,3,4,5,6,7,8

Recording for the Blind & Dyslexic
20 Roszel Rd
Princeton, NJ 08540
(609) 452-0606
(609) 520-7990 (fax)
2; extensive lending library of academic textbooks on audiocassette (all levels)

DYSOSTOSIS, ACROFACIAL, NAGER TYPE

See: Nager & Miller Syndromes

DYSOSTOSIS, MANDIBULOFACIAL

See: Nager & Miller Syndromes; Treacher Collins Syndrome

DYSOSTOSIS, METAPHYSEAL, TYPE B IV

See: Shwachman Syndrome

DYSOSTOSIS, POSTAXIAL ACROFACIAL

See: Nager & Miller Syndromes

DYSPLASTIC ANGIECTASIA, CONGENITAL

See: Klippel-Trenaunay Syndrome

DYSPRAXIA

See: Apraxia

DYSTONIA

Dystonia Medical Research Foundation
One E Wacker Dr, Ste 2230
Chicago, IL 60601-1905
(312) 755-0198
(312) 803-0138
dystfdtn@aol.com
http://www.ic.net/biz/dystonia.html
1,2,3,4,5,6,7,8,9

Dystonia Medical Research Foundation—Canada
116-230 Heath St W
Toronto, ON CAN M5P 1N8
(800) 361-8061 (Canada only)
(416) 487-8326
dystfdtn@aol.com
http://www.ic.net/biz/dystonia.html
1,2,3,4,5,7,8,9

DYSTROPHIC EPIDERMOLYSIS BULLOSA

See: Epidermolysis Bullosa, Dystrophic

EATON-LAMBERT SYNDROME

See: Muscular Dystrophy

ECTODERMAL DYSPLASIAS

Canadian Society for Ectodermal Dysplasia (Eastern Canada)
232 Macintosh Dr
Stoney Creek, ON CAN L8E 4C2
(905) 664-6121
2,3,4,9

Canadian Society for Ectodermal Dysplasia (Western Canada)
304 Hawkwood Blvd, NW
Calgary, AB CAN T3G 2Y5
(403) 239-0885
2,3,4,5,6,9

National Foundation for Ectodermal Dysplasias
219 E Main, PO Box 114
Mascoutah, IL 62258-0114
(618) 566-2020
(618) 566-4718 (fax)
nfed1@aol.com
1,2,3,4,6,7,8,9; financial assistance for treatment, scholarship program, regional conferences

ECTRODACTYLY-ECTODERMAL DYSPLASIA-CLEFT LIP/PALATE (EEC) SYNDROME

See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EEC SYNDROME

See: Cleft Palate; Craniofacial Disorders; Ectodermal Dysplasias

EHLERS-DANLOS SYNDROME

See also: Connective Tissue Disorders; Glaucoma; Visual Impairments

Ehlers-Danlos National Foundation
PO Box 35177
Los Angeles, CA 90035
(310) 277-4900
(310) 788-0742 (fax)
loosejoint@aol.com
http://www.phoenix.net/~leigh/EDS/
1,2,3,4,5,6,8,9

EINSTEIN SYNDROME

See: Hearing Impairments; Kidney Diseases, Hereditary; Vision Impairments

ELASTORRHEXIS

See: Connective Tissue Disorders

ELASTOSIS DYSTROPHICA SYNDROME

See: Pseudoxanthoma Elasticum (PXE)

ELLIS-VAN CREVELD SYNDROME

See: Ectodermal Dysplasias

EMERY-DREIFUSS MUSCULAR DYSTROPHY

See: Muscular Dystrophy

EMG SYNDROME

See: Beckwith-Wiedemann Syndrome

ENCEPHALITIS, CHRONIC LOCALIZED

See: Rasmussen Syndrome

ENCEPHALITIS & EPILEPSY, CHRONIC

See: Rasmussen Syndrome

ENCEPHALITIS, RASMUSSEN

See: Rasmussen Syndrome

ENCEPHALOFACIAL ANGIOMATOSIS

See: Sturge-Weber Syndrome

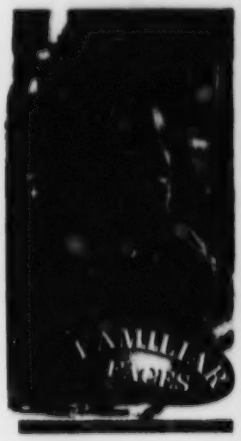
ENCEPHALOMYELOPATHY

See: Leigh Disease

ENCEPHALOMYELO-RADICULOPATHY, ACUTE DISSEMINATED

See: Guillain-Barre Syndrome

Eight-month-old Addison Clay Davis attempts a sleepy smile for the camera. Addison, who has Down syndrome, loves listening to music—with the everything from Mother Goose nursery rhymes to Bach. He also l making his own music—with the and pans in the kitchen! Now 18 months old, Addison lives in Bellflower, California with his par and his seven-year-old twin sister Ariana and Alina.



ENCEPHALOTRIGEMINAL ANGIOMATOSIS

See: Sturge-Weber Syndrome

ENCHONDROMATOSIS

See: Hemangioma; Ollier Disease

ENTEROPATHY, GLUTEN-SENSITIVE

See: Celiac Disease; Celiac Sprue; Gluten Intolerance

EOSINOPHILIC GRANULOMA

See: Histiocytosis

EPICANTHUS INVERSUS

See: Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)

EPIDERMOLYSIS BULLOSA, DYSTROPHIC

See also: Connective Tissue Disorders

DEBRA: Dystrophic Epidermolysis Bullosa Research Association
40 Rector St
New York, NY 10006
(212) 693-6610
(212) 693-6698 (fax)
1,2,3,4,5,6,7,8,9; Spanish materials

EPIDERMOLYTIC HYPERKERATOSIS

See: Ichthyosis

EPILEPSY

See also: Seizure Disorders

American Epilepsy Society
638 Prospect Ave
Hartford, CT 06105-4298
(203) 586-7505
(203) 586-7550 (fax)
1,6

Epilepsy Canada
1470 Peel St. Ste 745
Montreal, PQ CAN H3A 1T1
(514) 845-7855
(514) 845-7866 (fax)
1,2,5,6,8; French materials

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785-2267
(800) 332-1000
(800) 332-2070 (TTY)
(301) 459-3700
(301) 577-4941 (fax)
postmaster@efa.org
1,2,4,5,6,7,8

EPILOIA
See: Tuberous Sclerosis

ERB PALSY

Erb's Palsy Support and Information Network
8347 Valley View Ct
Larsen, WI 54947
(414) 836-3843
1,2,3,4,6,9

ERB/DUCHENNE PALSY
See: Erb Palsy

ERDHEIM-CHESTER DISEASE
See: Histiocytosis

ERYTHROBLASTOPHTHISIS
See: Anemia, Aplastic

ERYTHROBLASTOTIC ANEMIA OF CHILDHOOD
See: Cooley Anemia

ERYTHROHEPATIC PROTOPORPHYRIA
See: Liver Disorders: Porphyria

ERYTHROKERATODERMIAS
See: Ichthyosis

ERYTHROPHAGOCYTIC LYMPHOHISTIOCYTOSIS, FAMILIAL
See: Histiocytosis

ESOPHAGEAL ATRESIA
See: VATER/L Association

EVANS SYNDROME
See also: Autoimmune Disorders; Neutropenia

Evans Syndrome Support and Research Group
c/o Lou Addington
5630 Devon St
Port Orange, FL 32127
(904) 760-3031
(904) 760-5583 (fax)
73142.1315@compuserve.com
2,3,4,9

EXOMPHALOS-MACROGLOSSIA-GIGANTISM (EMG) SYNDROME
See: Beckwith-Wiedemann Syndrome

EXOMPHALOS-MACROGLOSSIA-GIGANTISM SYNDROME
See: Beckwith-Wiedeman Syndrome

EXOSTOSES, MULTIPLE HEREDITARY

MHE Family Support Group
1727 Ironwood Dr
Idaho Falls, ID 83402
(208) 523-6459
1,2,3,4

EXTERNAL CHONDROMATOSIS SYNDROME
See: Exostoses, Multiple Hereditary

EXTRACORPOREAL MEMBRANE OXYGENATION

ECMO Moms and Dads International Parent Support
PO Box 53848
Lubbock, TX 79453
(806) 794-0259
1,2,3,4,5,9

FABRY DISEASE
See also: Tay-Sachs Disease

International Center for Fabry Disease
Dept of Human Genetics
Mt Sinai School of Medicine
Box 1203
New York, NY 10029
(212) 241-6944
(212) 348-5811 (fax)
1,2,3,7

FACIAL DISFIGUREMENT
See: Craniofacial Disorders

FACIAL-DIGITAL-GENITAL SYNDROME
See: Aarskog Syndrome

FACIO-AURICULO-VERTEBRAL ANOMALY
See: Goldenhar Syndrome

FACIO-CARDIO-CUTANEOUS SYNDROME
See: Cardio-Facio-Cutaneous Syndrome

FACIO-SCAPULO-HUMERAL MUSCULAR DYSTROPHY
See also: Muscular Dystrophy

Facio-Scapulo-Humeral Society
3 Westwood Rd
Lexington, MA 02173
(617) 860-0501
1,2,3,4,6,7,8,9

FACIOGENITAL SYNDROME
See: Aarskog Syndrome

FAMILIAL ATAXIA
See: Ataxia; Friedreich Ataxia

FAMILIAL DYSAUTONOMIA

Dysautonomia Foundation
20 E 46th St, Rm 302
New York, NY 10017
(212) 949-6644
(212) 682-7625 (fax)
1,2,5,6,8,9

Dysautonomia Foundation
343 Clarke Ave W, Ste 1103
Thornhill, ON CAN L4J 7K5
(905) 882-7725
(905) 764-7752 (fax)
1,2,4,8,9

FAMILIAL PEMPHIGUS
See: Ichthyosis

FAMILIAL SPLENIC ANEMIA
See: Gaucher Disease

FANCONI ANEMIA
See: Anemia, Fanconi

FANCONI II
See: Cystinosis

FANCONI PANMYELOPATHY
See: Anemia, Fanconi

FARBER DISEASE
See: Tay-Sachs Disease

FAS/FAE
See: Fetal Alcohol Syndrome/Effect

FATTY OXIDATION DISORDER
See also: Metabolic Disorders

Support Group for FOD Families
805 Montrose Dr
Greensboro, NC 27410
(910) 547-8682
1,3

FEMALE SEX CHROMOSOME DISORDERS
See: Turner Syndrome

FETAL ALCOHOL SYNDROME/EFFECT

Family Empowerment Network: Supporting Families Affected by FAS/FAE
610 Langdon St, Rm 521
Madison, WI 53703
(800) 462-5254
(608) 262-6590
(608) 265-2329 (fax)
qwilton@facstaff.wisc.edu
1,2,3,4,6; Spanish materials

Fetal Alcohol Education Program
7 Kent St
Brookline, MA 02146
(617) 739-1424
1,2,3,4,6,7,9

Fetal Alcohol Support Network
614 Arbor Rd
Mississauga, ON CAN L5G 2J9
(905) 274-7700 (voice/fax)
1,2,3,4,9

Fetal Alcohol Syndrome Family Resource Institute
PO Box 2525
Lynnwood, WA 98036
(206) 531-2878
(206) 640-9155 (fax)
1,2,3,4,6,7,9

National Organization on Fetal Alcohol Syndrome
1815 H St NW, Ste 1000
Washington, DC 20006
(202) 785-4585
(202) 466-6456 (fax)
1,2,4,6,7

Support and Education Network for FAS Parents and Caregivers
c/o Bergen Cty Council on Alcoholism & Drug Abuse
PO Box 626
Paramus, NJ 07653
(201) 261-2183
(201) 261-0807 (fax)
2,3,4; group includes many foster/adoptive parents

FETAL FACE SYNDROME
See: Robinow Syndrome

FETAL IRITIS SYNDROME
See: Norrie Disease

FIBRODYSPLASIS OSSIFICANS PROGRESSIVA

International Fibrodysplasia Ossificans Progressiva Association
910 N Jericho Dr
Casselberry, FL 32707
(407) 365-4194 (voice/fax)
1,2,3,4,8,9

FIBROMYALGIA
See: Arthritis

FIBROUS ANKYLOSIS OF MULTIPLE JOINTS
See: Arthrogryposis Multiplex Congenita

FIBROUS DYSPLASIA, MONOSTOTIC
See: McCune-Albright Syndrome

FIBROUS DYSPLASIA, POLYOSTOTIC
See: McCune-Albright Syndrome

FIBULAR HEMIMELIA
See: Limb Disorders

FIRST AND SECOND BRANCHIAL ARCH SYNDROME
See: Goldenhar Syndrome

FISCHER SYNDROME
See: Guillain-Barre Syndrome

FISCHER-JACOBSEN-CLOUSTON SYNDROME
See: Ectodermal Dysplasias

FOCAL DERMAL HYPOPLASIA (FDH) SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias; Hearing Impairments

FOLATE METABOLISM; INBORN ERROR OF
See: Cobalamin (B12) Deficiency

FOOD ALLERGY
See also: Asthma & Allergy

The Food Allergy Network
10400 Eaton Pl, Ste 107
Fairfax, VA 22030-2208
(703) 691-3179
(703) 691-2713 (fax)
http://www.foodallergy.org
1,2,6,7,9

FORBES DISEASE
See: Glycogen Storage Diseases; Muscular Dystrophy

FRAGILE X SYNDROME
See also: Attention Deficit Disorder; Autism; Learning Disabilities

FraXa Research Foundation
PO Box 935
West Newbury, MA 01985
(508) 462-1990
(508) 463-9985 (fax)
fraxa@seacoast.com
http://www.worx.net/fraxa
1,2,3,5,7,8,9; Internet mailing list

National Fragile X Foundation
1441 York St, Ste 303
Denver, CO 80206
(800) 688-8765
(303) 333-6155
(303) 333-4369 (fax)
1,2,3,4,6

FRANCHESCHETTI-KLEIN SYNDROME
See: Treacher Collins Syndrome

FRAXA
See: Fragile X Syndrome

FREDREICH DISEASE
See: Ataxia; Friedreich Ataxia

FREDREICH TABES
See: Ataxia; Friedreich Ataxia

FREEMAN-SHELDON SYNDROME
See also: Craniofacial Disorders

Freeman-Sheldon Parent Support Group
509 E Northmont Wy
Salt Lake City, UT 84103
(801) 364-7060
fspsg@aol.com
1,2,3,4,7,9

FRIEDREICH ATAXIA
See also: Ataxia; Muscular Dystrophy

Canadian Association of Friedreich's Ataxia
5620 C A Jobin Rd
St Leonard, PQ CAN H1P 1H8
(514) 321-8684
1,6,7,8,9; French materials

FUCOSIDOSIS
See: Tay-Sachs Disease

FULLER-ALBRIGHT SYNDROME
See: McCune-Albright Syndrome

FULMINATING HYPERPYREXIA
See: Malignant Hyperthermia

G SYNDROME
See: Opitz Syndrome

GALACTOSE-1-PHOSPHATE URIDYL TRANSFERASE DEFICIENCY
See: Galactosemia

GALACTOSEMIA
See also: Metabolic Disorders

Parents of Galactosemic Children
2871 Stagecoach Dr
Valley Springs, CA 95252
(209) 772-2449 (voice/fax)
1,2,3,7,8

GARDNER SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

GASTROESOPHAGEAL REFLUX
See: Intestinal Pseudo-Obstruction Syndrome

GASTROINTESTINAL CANCER
See: Peutz-Jeghers Syndrome; Polyposis

GAUCHER DISEASE
See also: Tay-Sachs Disease

International Patient Advocacy Association
900 Bellevue Wy
MGM Bldg, Ste 400
Bellevue, WA 98004
(800) 944-7823, ext 4037
(206) 462-4037
(206) 462-9532 (fax)
1,2,3,4,5,6,7,9

National Gaucher Foundation
11140 Rockville Pike, Ste 350
Rockville, MD 20852-3106
(800) 925-8885
(301) 816-1515
(301) 816-1516 (fax)
1,2,3,4,5,6,7,8,9

GENEE-WIEDEMANN SYNDROME
See: Nager & Miller Syndromes

GENITALIA, AMBIGUOUS
See also: Hermaphroditism

Ambiguous Genitalia Support Network
428 E Elm St, #40
Lodi, CA 95240-2310
(209) 369-0414 (voice/fax)
2,3,4,5,7,9

GILFORD SYNDROME
See: Progeria

GINGIVAL FIBROMATOSIS AND HYPERTRICHOSIS
See: Ectodermal Dysplasias

GIROUX-BARBEAU SYNDROME
See: Ichthyosis

GLAUCOMA
See also: Visual Impairments

Glaucoma Research Foundation
490 Post St, Ste 830
San Francisco, CA 94102
(800) 826-6693
(415) 986-3162
(415) 986-3763 (fax)
1,2,3,4,6,8,9

GLUCOSE TRANSPORTER PROTEIN DEFICIT

The Will Foundation
c/o Molly McKenna
1320 N Elm Tree Rd
Lake Forest, IL 60045
(708) 234-5409
2,3,4,6,7,8,9

GLUCOSYL CEREBROSIDE LIPIDOSIS
See: Gaucher Disease

GLUTARIC ACIDURIA, TYPE I
See also: Acidemia, Organic; Lactic Acidosis

International Organization for Glutaric Aciduria, Type I
c/o Mike Metil and Cay Welch
RD 3, Box 167A
Jersey Shore, PA 17740
(717) 321-6487
1,2,3,6,9

GLUTARICACIDURIA I
See: Glutaric Aciduria, Type I

GLUTARICACIDURIA II
See: Acidemia, Organic; Lactic Acidosis

GLUTEN INTOLERANCE
See also: Celiac Disease; Celiac Sprue

Gluten Intolerance Groups of North America
PO Box 23053
Seattle, WA 98102-0353
(206) 325-6980
(206) 850-2394 (fax)
1,2,3,4,6,7,9; Spanish materials

GLUTEN-SENSITIVE ENTEROPATHY
See: Celiac Disease; Celiac Sprue; Gluten Intolerance

GLYCOGEN STORAGE DISEASES
See also: Hypoglycemia

Association for Glycogen Storage Disease
PO Box 896
Durant, IA 52747
(319) 785-6038 (voice/fax)
1,2,3,8,9

GLYCOGENOSES
See: Glycogen Storage Diseases

GLYCOSPHINGOLIPIDOSES
See: Tay-Sachs Disease

GOLDENHAR SYNDROME
See also: Craniofacial Disorders

Goldenhar Syndrome Research & Information Fund
1202 N 75th St, #127
Downers Grove, IL 60516
(813) 896-3232
(813) 896-2525 (fax)
2,4,8,9

GOLDENHAR-GORLIN SYNDROME
See: Goldenhar Syndrome

GOLDFLAM DISEASE
See: Myasthenia Gravis

GONADAL DYGENESIS (45,X)
See: Turner Syndrome

GORLIN-CHAUDHRY-MOSS SYNDROME
See: Ectodermal Dysplasias

GRANULOMA, EOSINOPHILIC
See: Histiocytosis

GRANULOMATOUS DISEASE, CHRONIC
See also: Immune Disorders

Chronic Granulomatous Disease Association
c/o Mary Hurley
2616 Monterey Rd
San Marino, CA 91108
(818) 441-4118
1,2,3,4,7,9

GRAVES DISEASE
See: Thyroid Disorders

GROENBLAD-STRANDBERG SYNDROME
See: Pseudoxanthoma Elasticum (PXE)

GROUP B STREP

Canadian Group B Strep Association
c/o Donna Vicny
343 Watson Ave
Windsor, ON CAN N8S 3S3
(519) 948-6324
2,3,9

Group B Strep Association
PO Box 16515
Chapel Hill, NC 27516
(919) 932-5344 (voice/fax)
1,2,3,4,5,6,7

GROWTH DISORDERS
See also: Dwarfism; Short Stature

Human Growth Foundation
7777 Leesburg Pike, Ste 202 S
Falls Church, VA 22043
(800) 451-6434
(703) 883-1773
(703) 883-1776 (fax)
1,2,3,4,5,8; Spanish materials

Little People's Research Fund
80 Sister Pierre Dr
Towson, MD 21204
(800) 232-5773
(410) 494-0055
(410) 494-0060 (fax)
1,2,4,6,7,9

MAGIC Foundation for Children's Growth
1327 N Harlem Ave
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808
(708) 383-0899 (fax)
magic@inettap.com
1,2,3,4,6,9; Spanish materials, pen pal program for children

GROWTH HORMONE DEFICIENCY
See: Growth Disorders

GROWTH RETARDATION, INTRAUTERINE
See: Growth Disorders

GUERIN-STERN SYNDROME
See: Arthrogryposis Multiplex Congenita

GUILLAIN-BARRE SYNDROME

Guillain-Barre Syndrome Support Group of Canada
Brennerman Filing System Ltd
3-50 Bathurst
Waterloo, ON CAN N2V 2C5
(519) 747-5777
(519) 747-5987 (fax)
1,2,3,4,5,6,8

GUNTHER PORPHYRIA
See: Porphyria

GUY-PATIN SYNDROME
See: Fibrodysplasia Ossificans Progressiva

HADDAD SYNDROME
See: Central Hypoventilation Syndrome, Congenital

HAILEY-HAILEY DISEASE
See: Ichthyosis

HAIRY ELBOWS DYSPLASIA
See: Ectodermal Dysplasias

HALL-PALLISTER SYNDROME
See: Pallister-Hall Syndrome

KEY TO SERVICES
1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

HALLERMAN-STREIFF SYNDROME
See: Craniofacial Disorders; Ectodermal Dysplasias; Short Stature

HALLOPEAU-SIEMENS DISEASE
See: Epidermolysis Bullosa Dystrophic

HAND-SCHULLER-CHRISTIAN SYNDROME
See: Histiocytosis

HAND-SHOULDER SYNDROME
See: Reflex Sympathetic Dystrophy Syndrome

HARLEQUIN ICHTHYOSIS
See: Ichthyosis

HAY-WELLS SYNDROME
See: Cleft Palate; Craniofacial Disorders; Deaf-Blind; Ectodermal Dysplasias; Hearing Impairments; Visual Impairments

HAYDEN SYNDROME
See: Ectodermal Dysplasias

HEAD INJURY
See: Brain Injury

HEARING IMPAIRMENT/VISUAL IMPAIRMENT
See: Deaf-Blind

HEARING IMPAIRMENTS

Alexander Graham Bell Association for the Deaf
3417 Volta Pl NW
Washington, DC 20007-2778
(202) 337-5220 (V/TTY)
1,2,3,6,7; Spanish materials, scholarship programs

American Society for Deaf Children
2848 Arden Wy, Ste 210
Sacramento, CA 95825-1373
(800) 942-2732 (V/TTY)
(916) 482-0121 (fax)
asdc1@aol.com
1,2,3,4,6,7

Auditory-Verbal International
2121 Eisenhower, Ste 402
Alexandria, VA 22314
(703) 739-1049
(703) 739-0874 (TTY)
(703) 739-0395 (fax)
1,2,3,4,6,7

Better Hearing Institute
PO Box 1840
Washington, DC 20013
(800) 327-9355 (V/TTY)
(703) 750-9302 (fax)
1,2,7; Spanish materials

Better Hearing Institute—Canada
146 Strathearn Rd
Toronto, Ontario CAN M6C 1S1
(800) 327-9355 (Canada only)
(703) 642-0580
(703) 750-9302 (fax)
1,2,4

Canadian Hard of Hearing Association
2435 Holly Ln, Ste 205
Ottawa, ON CAN K1V 7P2
(800) 263-8068 (Canada only)
(613) 526-1584
(613) 526-2692 (TTY)
(613) 526-4718 (fax)
chhanational@cyberus.ca
1,2,3,4,6,7,8; French materials

Canadian Hearing Society
271 Spadina Rd
Toronto, ON CAN M5R 2V3
(416) 964-9595
(416) 928-2506
(416) 964-0023 (TTY)
(416) 964-2066 (fax)
headoffice@chs.ca
1,2,3,4,5,6,7,8,9; French/Italian/Portuguese/Chinese materials

Cochlear Implant Club International
PO Box 464
Buffalo, NY 14223
(716) 838-4662 (V/TTY/fax)
76207.3114@compuserve.com
1,2,3,4,5,6,7,8

HEAR Now
9745 E Hampden Ave, Ste 300
Denver, CO 80231-4923
(800) 648-4327 (V/TTY)
(303) 695-7797 (V/TTY)
(303) 695-7789 (fax)
76350.650@compuserve.com
1,2,7; accepts tax-deductible donations of used hearing aids

John Tracy Clinic
806 W Adams Blvd
Los Angeles, CA 90007
(800) 522-4582 (V/TTY)
(213) 748-5481
(213) 747-2924 (TTY)
(213) 749-1651 (fax)
1,2,4,6,8; free correspondence course for preschoolers; Spanish materials

NAD: National Association of the Deaf
814 Thayer Ave
Silver Spring, MD 20910-4500
(301) 587-1788
(301) 587-1789 (TTY)
(301) 587-1791 (fax)
1,2,4,6,7; youth program includes Jr NAD clubs and Youth Leadership Camp

National Cued Speech Association
PO Box 31345
Raleigh, NC 27622
(919) 828-1218 (V/TTY)
(919) 828-1862 (fax)
ncsa@aol.com
1,2,3,4,5,6,7

NIDCD Hereditary Hearing

Impairment Resource Registry
555 N 30th St
Omaha, NE 68131
(800) 320-1171 (V/TTY)
(402) 498-6331 (fax)
nidcd.hhirr@boystown.org
http://www.boystown.org/hhirr/
1,2,9

SHHH: Self Help for Hard of Hearing People
7910 Woodmont Ave, Ste 1200
Bethesda, MD 20814
(301) 657-2248
(301) 657-2249 (TTY)
(301) 913-9413 (fax)
shhh.nancy@genie.com
1,2,4,5,7

Signing Exact English (SEE) Center for the Advancement of Deaf Children
PO Box 1181
Los Alamitos, CA 90720
(310) 430-1467 (V/TTY)
(310) 795-6614 (fax)
2,4,6

Telecommunications for the Deaf, Inc
8719 Colesville Rd, Ste 300
Silver Spring, MD 20910
(301) 589-3786
(301) 589-3006 (TTY)
(301) 589-3797 (fax)
sonnytdi@aol.com
1,2,6,7

TRIPOD Grapevine
2901 N Keystone St
Burbank, CA 91504
(800) 352-8888 (V/TTY)
(800) 287-4763 (V/TTY, CA only)
(818) 972-2090 (fax)
tripodla@aol.com
2,3,4

HEART DISORDERS

American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
(800) 242-8721
chuckh@amhrt.org
http://www.amhrt.org
2,3,4,5,6,7,8; Spanish materials

CHASER: Congenital Heart Anomalies—Support, Education, & Resources
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
myer106w@wonder.em.cdc.gov
1,2,3,4,7,9

Children's Heart Association for Support and Education
c/o Cardiac Clinic
Hosp for Sick Children
555 University Ave
Toronto, ON CAN M5G 1X8
(416) 813-5848
1,3,9

Heart and Stroke Foundation of Canada
160 George St, Ste 200
Ottawa, ON CAN K1N 9M2
(613) 241-4361
(613) 234-3278 (fax)
2,4,5,6,7,8; French materials

Heart Beats
c/o Children's Society of Calgary
Box 30233, Chinook Postal Outlet
Calgary, AL CAN T2H 2V9
(403) 286-9078
(403) 239-3254 (fax)
1,2,3,4,7,9

HEMANGIOMA

See also: Craniofacial Disorders; Vascular Malformations

Hemangioma Hope
c/o Cindy Dougan
8400 Rohl Rd
North East, PA 16428
(814) 898-1054
1,2,3,6

HEMATURIA, RENAL

See: IgA Nephropathy

HEMIDYSPLASIA, UNILATERAL

See: Ichthyosis

HEMIFACIAL MICROSOMIA

See: Goldenhar Syndrome

HEMIHYPERTROPHY

See: Beckwith-Wiedeman Syndrome

HEMIPLEGIA, ALTERNATING

See also: Epilepsy; Seizure Disorders

International Foundation for Alternating Hemiplegia of Children
29 Leonard Rd
Melrose, MA 02176
(617) 665-8906
1,2,8,9

HEMOLYTIC ANEMIA

See: Cooley Anemia

HEMOLYTIC-UREMIC SYNDROME

See: Kidney Disorders

HEMOPHAGOCYTIC LYMPHOHISTIOCYTOSIS

See: Histiocytosis

HEMOPHAGOCYTIC RETICULOSIS

See: Histiocytosis

HEMOPHILIA

Canadian Hemophilia Society
625 President Kennedy, Ste1210
Montreal, PQ CAN H3A 1K2
(800) 668-2686 (Canada only)
(514) 848-0503, ext 24
(514) 848-9661 (fax)
1,2,3,4,5,6,7,8; French materials

National Hemophilia Foundation
110 Greene St, Rm 303
New York, NY 10012
(800) 424-2639
(212) 219-8180
(212) 966-9247 (fax)
1,2,3,4,5,6,7,8; Spanish materials

World Federation of Hemophilia
1310 Green Ave, Ste 500
Montreal, PQ CAN H3Z 2B2
(514) 933-7944
(514) 933-8916 (fax)
wfh@wfh.org
1,2,4,6,8; worldwide referrals, guide for travelers

HEMORRHAGIC NODULAR PURPURA

See: Fabry Disease

HEMORRHAGIC TELANGIECTASIS, HEREDITARY

See also: Anemia, Aplastic; Vascular Malformations

HHT Foundation International
PO Box 8087
New Haven, CT 06530
(800) 448-6389 (US only)
(313) 561-2537 (US)
(313) 561-4585 (US, fax)
(604) 596-3418 (Canada)
(604) 596-0138 (Canada, fax)
lenke@deepcove.com
1,2,3,4,5,6,7,8,9

HEPATIC DUCTULAR HYPOPLASIA, SYNDROMATIC

See: Alagille Syndrome

HEPATOLENTICULAR DEGENERATION

See: Wilson Disease

HEPATOPHOSPHORYLASE DEFICIENCY GLYCOGENOSIS

See: Glycogen Storage Diseases; Muscular Dystrophy

HEREDITARY HEMORRHAGIC TELANGIECTASIS (HHT)

See: Hemorrhagic Telangiectasis, Hereditary

HEREDITARY KIDNEY DISEASES

See: Kidney Diseases, Hereditary

HEREDITARY LEPTOCYTOSIS

See: Cooley Anemia

HERMANSKY-PUDLAK SYNDROME

See also: Albinism & Hypopigmentation; Visual Impairments

Hermansky-Pudlak Syndrome Network
1 South Rd
Oyster Bay Cove, NY 11771
1,2,3,6,7,8,9; Spanish materials

HERMAPHRODITISM

See also: Genitalia, Ambiguous

Intersex Society of North America
PO Box 31791
San Francisco, CA 94131
(415) 436-0585
info@isna.org
1,2,3,5

HERNIA, DIAPHRAGMATIC

CHERUBS
c/o Dawn M. Torrence
3671 Bruce Garnder Rd
Franklinton, NC 27525
1,2,3,4,9

HERS DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

HIRSCHSPRUNG DISEASE

See: Intestinal Pseudo-Obstruction Syndrome

HISTIOCYTOSIS

See also: Growth Disorders; Liver Disorders; Lung Disorders; Pituitary Disorders

Histiocytosis Association of America
302 N Broadway
Pitman, NJ 08071
(800) 548-2758
(609) 589-6614 (fax)
1,2,3,4,6,8,9; Spanish/Russian materials

Histiocytosis Association of Canada
2316 Glastonbury Rd
Burlington, Ontario CAN L7P 3Y3
(905) 335-2172
1,2,3,6,8,9

HIV

See: AIDS

HODGKIN DISEASE

See: Leukemia

HOLOPROSENCEPHALY

See also: Craniofacial Disorders

Holoprosencephaly—Fighters of Defects Support Group
3032 Brereton St
Pittsburgh, PA 15219
(412) 687-6437
svwn61a@prodigy.com
1,2,3,4,9

HUMAN IMMUNODEFICIENCY VIRUS

See: AIDS

HUNTER SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HURLER SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HURLER/SCHEIE SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

HUTCHINSON-GILFORD SYNDROME

See: Progeria

HUTCHINSON-WEBER-PEUTZ SYNDROME

See: Peutz-Jeghers Syndrome; Polyposis

HYDROCEPHALUS

Guardians of Hydrocephalus Research Foundation
2618 Ave Z
Brooklyn, NY 11235
(800) 458-8655
(718) 743-4473
(718) 743-1171 (fax)
1,2,3,4; Spanish materials

Hydrocephalus Association
870 Market St, Ste 955
San Francisco, CA 94102
(415) 776-4713 (voice/fax)
1,2,3,6,7,8,9; Spanish materials

Hydrocephalus Support Group
PO Box 4236
Chesterfield, MO 63006-4236
(314) 532-8228
1,2,3,4,6,7,9

National Hydrocephalus Foundation
1670 Green Oak Cir
Lawrenceville, GA 30243
(800) 431-8093
1,2,3,5

HYDROCEPHALUS, OBSTRUCTIVE

See: Dandy-Walker Syndrome

HYPERAMMONEMIA

See: Urea Cycle Disorders

HYPERCALCEMIA SYNDROME, INFANTILE, IDIOPATHIC

See: Williams Syndrome

HYPERCALCEMIA-SUPRAVALVAR AORTIC STENOSIS

See: Williams Syndrome

HYPERCYSTINURIA

See: Cystinuria

HYPERGLYCINEMIA WITH KETOACIDOSIS AND LEUKOPENIA

See: Acidemia, Organic

HYPERLEXIA

See also: Autism; Language Disorders

American Hyperlexia Association
479 Spring Rd
Elmhurst, IL 60126
(708) 530-8551
(708) 530-5909 (fax)
whaley@one.net
http://www.hyperlexia.org
1,2,3,4,6

Canadian Hyperlexia Association
c/o 3266 Yonge St, #1829
Toronto, ON CAN M4N 3P6
(905) 886-8364
(416) 487-2883
(416) 487-3591 (fax)
1,2,3,4,5,6,9

HYPEROXALURIA

See: Oxalosis & Hyperoxaluria

HYPERTELORISM/HYPOSPADIUS SYNDROMES

See: Opitz Syndrome

HYPERTHERMIA OF ANESTHESIA

See: Malignant Hyperthermia

HYPERTHYROID MYOPATHY

See: Muscular Dystrophy; Thyroid Disorders

HYPERURICEMIA-CHOREOATHETOSIS-SELF-MUTILATION SYNDROME

See: Lesch-Nyhan Disease

HYPERURICEMIA, HEREDITARY

See: Lesch-Nyhan Disease

HYPOERYTHEMIA, PROGRESSIVE

See: Anemia, Aplastic

HYPOGAMMAGLOBULINEMIA

See: Immune Disorders

HYPOGLYCEMIA

See also: Diabetes Mellitus

National Hypoglycemia Association
PO Box 120
Ridgewood, NJ 07451
(201) 670-1189
2,3,4,7

HYPOMELANOSIS OF ITO

See: Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti; Vitiligo

HYPOMYELINATION

See: Myelin Disorders; Myelin, Insufficient

HYPOPARATHYROIDISM

See also: Thyroid Disorders

Hypoparathyroidism Newsletter
2835 Salmon St
Idaho Falls, ID 83406
(208) 524-3857
ruta59a@prodigy.com
1,3

HYPOPIGMENTATION

See: Albinism & Hypopigmentation; Vitiligo

HYPOPLASIA OF THE CORPUS CALLOSUM

See: Agenesis of the Corpus Callosum

HYPOPLASTIC ANEMIA

See: Anemia, Aplastic

HYPOPLASTIC LEFT HEART SYNDROME

See: Heart Disorders

HYPOSPADIUS/HYPERTELORISM SYNDROMES

See: Opitz Syndrome

HYPOTHYROID MYOPATHY

See: Muscular Dystrophy; Thyroid Disorders

HYPOTHYROIDISM, CONGENITAL

See: Growth Disorders; Thyroid Disorders

HYPOTONIA, BENIGN CONGENITAL

See: Spinal Muscular Atrophy

I-CELL DISEASE

See: Mucopolysaccharidosis; Tay-Sachs Disease

ICHTHYOSIS

FIRST: Foundation for Ichthyosis and Related Skin Types
PO Box 20921
Raleigh, NC 27619
(800) 545-3286
(919) 782-5728
(919) 781-0679 (fax)
74722.1571@compuserve.com
1,2,3,4,6,7,9; Spanish materials

IDIOPATHIC THROMBOCYTOPENIA PURPURA (ITP)

See: Purpura, Idiopathic Thrombocytopenia (ITP)

IDIOSYNCRATIC PORPHYRIA

See: Porphyria

IGA NEPHROPATHY

See also: Kidney Disorders

IgA Nephropathy Support Network
234 Summit Ave
Jenkintown, PA 19046
(215) 884-9038
(215) 884-8763 (fax)
70651.3254@compuserve.com
1,2,3,4,5,7,8,9

ILLIOSTOMY

See: Ostomy

ILLNESS, TERMINAL

See also: Bereavement Support

Children's Hospice International
1850 M St, NW, Ste 900
Washington, DC 20036
(800) 242-4453
(703) 684-0330
(703) 684-0226 (fax)
1,2,4,6,7

IMMUNE DEFICIENCY

See: Immune Disorders

IMMUNE DISORDERS

See also: Autoimmune Disorders

Immune Deficiency Foundation
25 W Chesapeake Ave, Ste 206
Towson, MD 21204
(800) 296-4433
(410) 321-6647
(410) 321-9165 (fax)
idf@clark.net
1,2,3,4,5,6,8,9; Spanish/German/French materials

IMPERFORATE ANUS

See: Anorectal Malformations

INCONTINENCE

Help for Incontinent People
PO Box 8310
Spartanburg, SC 29305
(800) 252-3337
(803) 579-7900
(803) 579-7902 (fax)
1,2,4,7; Spanish materials

Simon Foundation for Continence
PO Box 815
Wilmette, IL 60091
(800) 237-4666
(708) 864-3913
(708) 864-9758 (fax)
1,2,4,7

Simon Foundation for Continence—Canada
PO Box 66524
Cavendish Mall
Cote St Luc, PQ CAN H4W 3J6
(800) 265-9575 (Canada only)
(514) 923-6060
(514) 923-8852 (fax)
1,2,4

INCONTINENTIA PIGMENTI

See also: Ectodermal Dysplasias

IP Support Network
c/o Colleen Kidder
34929 Elm
Wayne, MI 48184
(313) 729-7912
1,2,3

National Incontinentia Pigmenti Foundation
41 E 57th St, 5th Fl
New York, NY 10022
(212) 207-4636
(212) 371-7345 (fax)
nipf@pipeline.com
1,2,3,4,6,9

INCONTINENTIA PIGMENTI ACHROMIANS

See: Ectodermal Dysplasias; Epilepsy; Incontinentia Pigmenti

INDIA RUBBER SKIN

See: Ehlers-Danlos Syndrome

INFANTILE FACIO-SCAPULO-HUMERAL MUSCULAR DYSTROPHY

See: Facio-Scapulo-Humeral Muscular Dystrophy

INFANTILE HYPERCALCEMIA SYNDROME, IDIOPATHIC

See: Williams Syndrome

All bundled up! Samuel May, 5 already to brave any blizzards t come his way! Samuel, who has fragile X syndrome, lives in Fairf Virginia. His mother Kathy descri him as a "fun-loving, bright youn child with a great sense of humo a lot of love to share." Samuel is first-grader at Poplar Tree Elementary School in Fairfax, wh he is enrolled in an autism prog His loves are Super Nintendo, hi trains and his trampoline.

INFANTILE SPASMS

See: Epilepsy

INTESTINAL NEURONAL DYSPLASIA

See: Intestinal Pseudo-Obstruction Syndrome

INTESTINAL POLYPOSIS

See: Peutz-Jeghers Syndrome; Polyposis

INTESTINAL POLYPOSIS-CUTANEOUS PIGMENTATION SYNDROME

See: Peutz-Jeghers Syndrome; Polyposis

INTESTINAL PSEUDO-OBSTRUCTION SYNDROME

American Pseudo-Obstruction and Hirschsprung's Disease Society
PO Box 772
Medford, MA 02155
(617) 395-4255
(617) 396-6868 (fax)
1,2,3,4,5,6,7,8,9

KEY TO SERVICES

1. Periodical/newsletter
2. Informational materials
3. Networking/matching
4. Referrals to local resources
5. Local chapters
6. National conferences
7. National advocacy efforts
8. Fund research
9. Maintain research registry

BEST COPY AVAILABLE

ASAP: American Society of Adults with Pseudo-Obstruction Young Adults Network
19 Carroll Rd
Woburn, MA 01801-6161
(617) 935-9776
(617) 933-4151 (fax)
caesar@interserv.com
1,2,3,4,6,9

INTRAHEPATIC BILE DUCT PAUCITY

See: Alagille Syndrome

INTRAUTERINE GROWTH RETARDATION

See: Growth Disorders

INTRAVENTRICULAR HEMORRHAGE

See also: Cerebral Palsy; Neonatal Illness/Prematurity

IVH Parents
PO Box 56-1111
Miami, FL 33256-1111
(305) 232-0381
(305) 232-9890 (fax)
72167.633@compuserve.com
1,3,7,9

ISOVALERIC ACIDEMIA (IVA)

See: Acidemia, Organic

ISOVALERYL-COA CARBOXYLASE DEFICIENCY

See: Acidemia, Organic

JANSKY-BIELSCHOWSKY DISEASE

See: Batten Disease; Tay-Sachs Disease

JEGHERS SYNDROME

See: Peutz-Jeghers Syndrome; Polyposis

JERVELL & LANGE-NIELSEN SYNDROME

See: Hearing Impairments; Long Q-T Syndrome

JEUNE SYNDROME

See: Growth Disorders

JOHANSON-BLIZZARD SYNDROME

See: Craniofacial Disorders; Ectodermal Dysplasias; Growth Disorders; Hearing Impairments; Short Stature

JORGENSON SYNDROME

See: Ectodermal Dysplasias

JOUBERT SYNDROME

See also: Apnea, Sleep

Joubert Syndrome Parents-in-Touch Network
12348 Summer Meadow Rd
Rock, MI 49880
(906) 359-4707
1,2,3,4,6

JUVENILE GOUT-CHOREOATHETOSIS-MENTAL RETARDATION SYNDROME

See: Lesch-Nyhan Disease

KALLMAN SYNDROME

See: Cleft Palate; Growth Disorders; Hearing Impairments; Kidney Disorders

KAST SYNDROME

See: Cancer; Hemangioma; Ollier Disease

KEARNS-SAYRE SYNDROME

See: Heart Disorders; Mitochondrial Disorders; Retinitis Pigmentosa; Visual Impairments

KERATITIS FOLLICULARIS SPINULOSA DECALVANS

See: Ectodermal Dysplasias; Ichthyosis

KERATITIS-ICHTHYOSIS-DEAFNESS (KID) SYNDROME

See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KETOACIDURIA

See: Maple Syrup Urine Disease

KETOTIC HYPERGLYCINEMIA

See: Acidemia, Organic

KID SYNDROME

See: Ectodermal Dysplasias; Ichthyosis; Hearing Impairments

KIDNEY DISEASES, HEREDITARY

See also: Cystinosis; IgA Nephropathy; Kidney Diseases; Hereditary; Oxalosis & Hyperoxaluria

Hereditary Nephritis Foundation
PO Box 57294
Murray, UT 84157-0294
(801) 262-1465
1,3,6,8,9

KIDNEY DISORDERS

See also: Cystinosis; IgA Nephropathy; Kidney Diseases; Hereditary; Oxalosis & Hyperoxaluria

American Association of Kidney Patients
100 S Ashley Dr, Ste 280
Tampa, FL 33602
(800) 749-2257
(813) 223-7099
(813) 223-0001 (fax)
aakpaz@enet.net
1,2,3,6,7,9

American Kidney Fund
6110 Executive Blvd, Ste 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-0898 (fax)
1,2,4,6,8; Spanish materials; financial assistance for treatment-related expenses

Canadian Pediatric Kidney Disease Research Center
401 Smith Rd
Ottowa, ON CAN K1H 8L1
(613) 737-4098
(613) 738-4800 (fax)
2,4

Kidney Foundation of Canada
5160 Blvd Decarie, Bureau 780
Montreal, PQ CAN H3X 2H9
(514) 369-4806
(514) 369-2472 (fax)
1,2,3,4,6,8; French/Chinese/Punjabi materials

National Kidney Foundation
30 E 33rd St, 11th Fl
New York, NY 10016
(800) 622-9010
(212) 889-2210
(212) 689-9261 (fax)
1,2,4,5,7,8

Polycystic Kidney Research Foundation
4901 Main St, Ste 320
Kansas City, MO 64112-2674
(800) 753-2873
(816) 931-2600
(816) 931-8655 (fax)
75713.2275@compuserve.com
1,4,5,6,7,8,9; Japanese/Italian/Spanish/German materials

Positive Renal Outreach
4901 Main St, Ste 320
Kansas City, MO 64112-2674
(800) 753-2873
(816) 931-2600
75713.2275@compuserve.com
1,2,5,6,7,8,9; Spanish/French/German/Italian/Japanese materials

KIDNEY STONES

See: Cystinuria

KILLIAN SYNDROME

See: Pallister-Killian Syndrome

KINKY HAIR DISEASE

See: Menkes Disease

KIRGHIZIAN DERMATOOSTEOLYSIS

See: Ectodermal Dysplasias

KLINEFELTER SYNDROME

49 XXXXY Syndrome Association
10001 NE 74th St
Vancouver, WA 98662-3801
(360) 892-7547
1,3,9

Klinefelter Syndrome and Associates
PO Box 119
Roseville, CA 95661-0119
raylstoc@ix.netcom.com
1,2,3,5,7,9; Spanish materials

Klinefelter's Syndrome Association of America
PO Box 93
Pine River, WI 54965
1,2,3

SEEKS: Support and Educational Exchange for Klinefelter Syndrome
1417 25th Ave Dr W
Bradenton, FL 34205-6449
(941) 750-8044
1,2,3,9

KLIPPEL-TRENAUNAY SYNDROME

See also: Nevi, Giant Congenital; Sturge-Weber Syndrome; Vascular Malformations

Klippel-Trenaunay Support Group
c/o Judy Vessey
4610 Wooddale Ave
Edina, MN 55424
(612) 925-2596
(612) 333-8685 (fax)
vesse001@staff.tc.umn.edu
1,2,3,4,6

KLIPPEL-TRENAUNAY-WEBER SYNDROME

See: Klippel-Trenaunay Syndrome

KRABBE DISEASE

See: Leukodystrophy; Tay-Sachs Disease

KUFS DISEASE

See: Batten Disease; Tay-Sachs Disease

KUGELBERG-WELANDER DISEASE

See: Spinal Muscular Atrophy

KUSSMAUL-LANDRY PARALYSIS

See: Guillain-Barre Syndrome

KYPHOSIS

See: Scoliosis

LACTATE DEHYDROGENASE DEFICIENCY

See: Muscular Dystrophy

LACTIC ACIDOSIS

See also: Glutaric Aciduria, Type I; Leigh Disease; Metabolic Disorders

Lactic Acidosis Support Group
1620 Mable Ave
Denver, CO 80229
(303) 287-4953
2,3,4,9

LAMBERT-EATON SYNDROME

See: Muscular Dystrophy

LANDAU-KLEFFNER SYNDROME

See also: Autism; Epilepsy; Language Disorders

CANDLE Support Group
4414 McCampbell Dr
Montgomery, AL 36106
(334) 271-3947 (voice/fax)
2,3,4,5,7,8,9; French materials

LANDOUZY-DEJERINE MUSCULAR DYSTROPHY

See: Facio-Scapulo-Humeral Muscular Dystrophy

LANDRY ASCENDING PARALYSIS

See: Guillain-Barre Syndrome

LANGER-GIEDION SYNDROME

See: Ectodermal Dysplasias; Exostoses, Multiple Hereditary

LANGERHANS CELL HISTIOCYTOSIS

See: Histiocytosis

LANGUAGE DISORDERS

See also: Aphasia, Acquired; Apraxia; Autism; Hyperlexia; Landau-Kleffner Syndrome; Stuttering

TALK: Taking Action Against Language Disorders for Kids
22980 Donna Ln
Bend, OR 97701
(503) 389-0004
1,2,3,4,9

LATEX ALLERGY

Canadian Latex Allergy Association
96 Cavan St
Port Hope, Ontario CAN L1A 3B7
(905) 885-5270
(905) 885-2839 (fax)
1,2,3,4,8,9

Latex Allergy Information Service
176 Roosevelt Ave
Torrington, CT 06790
(203) 482-6869
(203) 482-7640 (fax)
76500.1452@compuserve.com
1,3,4,5,7; provides regularly-updated list of latex-containing products

LAURENCE-MOON SYNDROME

See: Laurence-Moon-Bardet-Biedl Syndrome

LAURENCE-MOON-BARDET-BIEDL SYNDROME

See also: Kidney Disorders; Retinitis Pigmentosa

Laurence-Moon-Bardet-Biedl Syndrome Network
18 Strawberry Hill
Windsor, CT 06095
(203) 688-7880
1,2,8

LE JEUNE SYNDROME

See: Cri Du Chat Syndrome

LEARNING DISABILITIES

See also: Attention Deficit Disorder: Dyslexia: Learning Disabilities & Gifted

Learning Disabilities Association of America
4156 Library Rd
Pittsburgh, PA 15234
(412) 341-1515
(412) 344-0224 (fax)
1,2,4,5,6,7

Learning Disabilities Association of Canada
323 Chapel St, Ste 200
Ottawa, ON CAN K1N 7Z2
(613) 238-5721
(613) 235-5391 (fax)
idactaac@fox.nstn.ca
1,2,4,5,6,7; French materials

National Center for Learning Disabilities
381 Park Ave S, Ste 1420
New York, NY 10016
(212) 545-7510
(212) 545-9665 (fax)
1,2,4,7; Spanish materials

LEARNING DISABILITIES & GIFTED

See also: Attention Deficit Disorder: Dyslexia: Learning Disabilities

Parents of Gifted/LD Students
2420 Eccleston St
Silver Spring, MD 20902
(301) 986-1422
(301) 622-5163 (fax)
1,2,3,4,9

LEIGH DISEASE

See also: Lactic Acidosis: Mitochondrial Disorders

National Leigh's Disease Foundation
608 E Waldron St, PO Box 2222
Corinth, MS 38834
(800) 819-2551
(601) 286-2551 (fax)
1,2,3,4,5,6,7,8,9

LENTICULAR DEGENERATION, PROGRESSIVE

See: Wilson Disease

LENZ-PASSARGE DYSPLASIA

See: Ectodermal Dysplasias

LEPTOCYTOSIS, HEREDITARY

See: Cooley Anemia

LEPTOMENINGEAL ANGIOMATOSIS

See: Sturge-Weber Syndrome

LESCH-NYHAN DISEASE

International Lesch-Nyhan Disease Association
11042 Ferndale St
Philadelphia, PA 19116
(215) 677-4206
2,3

Lesch-Nyhan Registry
Dept of Psychiatry
New York Univ. School of Medicine
550 First Ave
New York, NY 10016
(212) 263-6458
(212) 629-9523 (fax)
andersni@is2.nyu.edu
2,3,6,9

LETTERER-SIWE DISEASE

See: Histocytosis

LEUKEMIA

See also: Bone Marrow Transplant: Cancer

Leukemia Research Fund
110 Finch Ave W, Ste 220
Toronto, ON CAN M3J 2T2
(800) 268-2144 (Canada only)
(416) 661-9541
(416) 661-7799 (fax)
1,4,5,6,8

Leukemia Society of America
600 Third Ave, 4th Fl
New York, NY 10016
(800) 955-4572
(212) 573-8484
(212) 856-9686 (fax)
1,2,3,4,5,7,8; Spanish materials

LEUKODYSTROPHY

See also: Myelin Disorders: Tay-Sachs Disease

United Leukodystrophy Foundation
2304 Highland Dr
Sycamore, IL 60178
(800) 728-5483
(815) 895-3211
(815) 895-2432 (fax)
(815) 895-8633 (BBS, 9600 baud)
ulf@ceet.niu.edu
1,2,3,4,6,8,9

LEUKODYSTROPHY, METACHROMATIC

See: Leukodystrophy: Tay-Sachs Disease

LIMB DISORDERS

See also: Amputation: Chorionic Villus Sampling: Related Disabilities

Cherub Association of Families and Friends of Children with Limb Disorders
936 Delaware Ave
Buffalo, NY 14209
(716) 762-9997
1,2,3; summer camp

Superkids Newsletter
60 Clyde St
Newton, MA 02160
1,3,9

LIMB-GIRDLE MUSCULAR DYSTROPHY

See: Muscular Dystrophy

LIMIT DEXTRINOSIS

See: Glycogen Storage Diseases: Muscular Dystrophy

LIPID HISTIOCYTOSIS

See: Niemann-Pick Disease

LIPIDOSIS, CEREBROSIDE

See: Gaucher Disease

LIPOFUSCINOSES, NEURONAL CEROID

See: Batten Disease

LIPOID HYPERPLASIA, CONGENITAL

See: Adrenal Hyperplasia, Congenital

LISSENCEPHALY

See also: Epilepsy

Lissencephaly Network
716 Autumn Ridge Ln
Fort Wayne, IN 46804
(219) 432-4310 (voice/fax)
1,2,3,6,9

Lissencephaly Network—Canada
1549 Regent St
Regina, SK CAN S4N 1S1
(306) 569-0146
1,2,3,4,6,9; toy-lending library

LIVER DISEASES

See: Liver Disorders

LIVER DISORDERS

See also: Biliary Atresia

American Liver Foundation
1425 Pompton Ave
Cedar Grove, NJ 07009
(800) 223-0179
(201) 256-2550
(201) 256-3214 (fax)
1,2,4,5,6,7,8,9; Spanish materials

Canadian Liver Foundation
365 Bloor St E, Ste 200
Toronto, ON CAN M4W 3L4
(800) 563-5483 (Canada only)
(416) 964-1953
(416) 964-0024 (fax)
1,2,5,8; French materials

United Liver Association
11646 W Pico Blvd
Los Angeles, CA 90064-2987
(310) 914-8252
(310) 575-3871 (fax)
1,2,3,8

LIVER PHOSPHORYLASE DEFICIENCY

See: Glycogen Storage Diseases: Muscular Dystrophy

LOBAR HOLOPROSENCEPHALY

See: Holoprosencephaly

LOBSTEIN DISEASE, TYPE I

See: Osteogenesis Imperfecta

LONG Q-T SYNDROME

See also: Heart Disorders

International Long QT Syndrome Registry
PO Box 653
University of Rochester Medical Ctr
Rochester, NY 14642-8653
(716) 275-5391
(716) 473-2751 (fax)
4,9

Sudden Arrhythmic Death Syndromes Foundation
540 Arapeen Dr, Ste 207
Salt Lake City, UT 84108
(800) 786-7723
(801) 582-1934
(801) 582-1941 (fax)
1,2,3,4

LORDOSIS

See: Scoliosis

LOWE SYNDROME

See also: Arthritis: Cystinuria: Glaucoma: Growth Disorders: Kidney Disorders: Metabolic Disorders: Visual Impairments

Lowe Syndrome Association
222 Lincoln St
W Lafayette, IN 47906
(317) 743-3634
kayeuulsa@aol.com
1,2,3,6,8,9

LOWE-BICKEL SYNDROME

See: Lowe Syndrome

LOWE-TERRY-MACHLACHLAN SYNDROME

See: Lowe Syndrome

LUNG DISEASES

American Lung Association
1740 Broadway
New York, NY 10019
(800) 586-4872
(212) 315-8700
(212) 265-5642 (fax)
2,4,5,6,7,8; Spanish materials

Canadian Lung Association
1900 City Park Dr, Ste 508
Gloucester, ON CAN K1J 1A3
(613) 747-6776
(613) 747-7430 (fax)
1,2,3,4,5,6,7,8

LUPUS ERYTHEMATOSIS

American Lupus Society
260 Maple Ct, Ste 123
Ventura, CA 93003
(800) 331-1802 (info line)
(805) 339-0443
(805) 339-0467 (fax)
1,2,4,5,8

Lupus Canada
PO Box 64034
5512 4th NW
Calgary, AL CAN T2K 6J1
(800) 661-1468
(403) 274-5599
1,2,4,5,6,7; French materials

Lupus Foundation of America
4 Research Pl, Ste 180
Rockville, MD 20850-3226
(800) 558-0121
(800) 558-0231 (Spanish)
(301) 670-9292
(301) 670-9486 (fax)
http://www.lupus.org/lupus
1,2,4,5,6,7,8; Spanish materials

SLE Foundation
149 Madison Ave, Ste 205
New York, NY 10016
(212) 685-4118
(212) 545-1843 (fax)
1,2,4,5,6,7,8; Spanish materials

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

LYME DISEASE

Lyme Disease Foundation
1 Financial Plaza, Gold Bldg, 18th Fl
Hartford, CT 06103-2610
(800) 886-5953 (info line)
(203) 525-2000
(203) 525-8425 (voice/fax)
1,2,4,6,7,8,9; Spanish materials

Lyme Disease Resource Center
PO Box 9510
Santa Rosa, CA 95405
(707) 575-5133
1,2,3,4,6; Spanish materials

LYMPHANGIOMA

See: Vascular Malformations

LYMPHANGIOMA, CAVERNOUS

See: Lymphatic Malformations

LYMPHATIC MALFORMATIONS

See also: Vascular Malformations

CALM: Children Anguished with Lymphatic Malformations
16 River Bend Rd
Montgomery, IL 60538
(708) 906-9028
1,3,4,9

LYMPHEDEMA

National Lymphedema Network
2211 Post St, Ste 404
San Francisco, CA 94115
(800) 541-3259
(415) 921-4284 (fax)
lymphnetx@hooked.net
http://www.primenet.com/~dean/lymph.html
1,2,3,4,6,7,9; Spanish materials

LYMPHOHISTIOCYTOSIS, FAMILIAL ERYTHROPHAGOCYTIC

See: Histocytosis

LYMPHOHISTIOCYTOSIS, HEMOPHAGOCYTIC

See: Histocytosis

LYMPHOHISTIOCYTOSIS, MALIGNANT

See: Cancer: Histocytosis

LYMPHOMA

See: Leukemia

MACULAR DISEASES

See also: Retinitis Pigmentosa; Stargardt Disease; Usher Syndrome; Visual Impairments

Association for Macular Diseases
210 E 64th St
New York, NY 10021
(212) 605-3719
(212) 605-3795 (fax)
1,2,4

Macular Degeneration Foundation
PO Box 686
Palm Beach, FL 33480
(407) 867-5825
(407) 867-9807 (fax)
mdfeyes@aimnet.com
1,2,4,9

MACULAR DYSTROPHIES, JUVENILE

See: Macular Diseases; Stargardt Disease

MAFFUCCI SYNDROME

See: Cancer; Hemangioma; Ollier Disease

MALE SEX CHROMOSOME DISORDERS

See: Klinefelter Syndrome

MALIGNANT HYPERTHERMIA

Malignant Hyperthermia Association
2 Bloor St W, Box 144
Toronto, ON CAN M4W 3E2
(416) 222-0150
(416) 224-0360 (fax)
1,2,8

Malignant Hyperthermia Association of United States
32 S Main St, PO Box 1069
Sherburne, NY 13460
(800) 986-4287
(607) 674-7901
(800) 674-7910 (fax)
1,2,8,9; Spanish/Italian/Portuguese materials

North American Malignant Hyperthermia Registry
Dept of Anesthesia, Penn State Univ
PO Box 850
Hershey, PA 17033
(717) 531-6936
(717) 531-6221 (fax)
9; provides physicians with summaries of consenting, registered patients' anesthesia histories

MANDIBULOFACIAL DYSOSTOSIS

See: Nager & Miller Syndromes; Treacher Collins Syndrome

MANNOSIDOSIS

See: Tay-Sachs Disease

MAPLE SYRUP URINE DISEASE

See also: Acidemia, Organic; Metabolic Disorders

Maple Syrup Urine Disease Family Support Group
24806 State Rd 119
Goshen, IN 46526
(219) 862-2992
(219) 862-2012 (fax)
1,2,3,4,6

Ontario Association for Maple Syrup Urine Disease Research
42 Alpha Mills Rd
Mississauga, ON CAN L5N 1H6
(905) 567-4188
2,3,4,6,8

MARDEN-WALKER SYNDROME

See: Cleft Palate; Connective Tissue Disorders; Growth Disorders

MARFAN SYNDROME

See also: Connective Tissue Disorders; Heart Disorders; Scoliosis

Canadian Marfan Association
Central Plaza PO
128 Queen St S, PO Box 42257
Mississauga, ON CAN L5M 4Z0
(905) 826-3223
(905) 826-2125 (fax)
1,2,4,5,6,7,8,9; French materials

National Marfan Foundation
382 Main St
Port Washington, NY 11050
(800) 862-7326
(516) 883-8712 (voice/fax)
1,2,3,5,6,7,8

MARKER X SYNDROME

See: Fragile X Syndrome

MAROTEAUX-LAMY SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

MARSHALL SYNDROME, TYPE I

See: Ectodermal Dysplasias

MARTIN-BELL SYNDROME

See: Fragile X Syndrome

MAST CELL DISEASE, SYSTEMIC

See: Mastocytosis

MASTOCYTOSIS

Mastocytosis Chronicles
4771 Waynes Trace Rd
Hamilton, OH 45011
(513) 726-4642
(513) 726-4605 (fax)
1,2,3

MCARDLE DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

MCCUNE-ALBRIGHT SYNDROME

See also: Growth Disorders

McCune-Albright Syndrome Division of the MAGIC Foundation
3167 Greensburg Rd
N Canton, OH 44720
(216) 896-4455 (voice/fax)
1,2,3,6,9

MEDITERRANEAN ANEMIA

See: Cooley Anemia

MEDIUM-CHAIN ACYL-COA DEHYDROGENASE DEFICIENCY (MCAD)

See: Fatty Oxidation Disorder

MEDULLOBLASTOMA, HEREDITARY

See: Brain Tumors

MEERKEREN-EHLERS-DANLOS SYNDROME

See: Ehlers-Danlos Syndrome

MEIGE DISEASE

See: Lymphedema

MELANOLEUCODERMA

See: Ectodermal Dysplasias

MELANOPLAKIA-INTESTINAL POLYPOSIS

See: Peutz-Jeghers Syndrome; Polyposis

MELAS SYNDROME

See: Growth Disorders; Lactic Acidosis; Mitochondrial Disorders

MELNICK NEEDLES SYNDROME

See: Growth Disorders

MEN SYNDROME I

See: Multiple Endocrine Neoplasia I

MENIERE SYNDROME

See: Crouzon Disease

MENINGEAL CAPILLARY ANGIOMATOSIS

See: Sturge-Weber Syndrome

MENKES DISEASE

See also: Liver Disorders; Metabolic Disorders

Corporation for Menkes Disease
5720 Buckfield Ct
Fort Wayne, IN 46804
(219) 436-0137
1,2,3,6,9; parent-professional network

MENTAL ILLNESS

See also: Mental Retardation/Mental Illness

Canadian Mental Health Association
2160 Yonge St
Toronto, ON CAN M4S 2Z3
(416) 484-7750
(416) 484-4617 (fax)
1,2,4,5,6,7; French materials

Federation of Families for Children's Mental Health
1021 Prince St
Alexandria, VA 22314-2971
(703) 684-7710
(703) 836-1040 (fax)
1,2,3,4,5,6,7; Spanish materials

National Alliance for the Mentally Ill
200 N Glebe Rd, Ste 1015
Arlington, VA 22203-3754
(703) 524-7600
(703) 524-9094 (fax)
http://www.cais.com/vikings/nami/index.html
1,2,3,4,5,6,7,8

National Mental Health Association
1021 Prince St
Alexandria, VA 22314-2971
(800) 969-6642 (info line)
(703) 684-7722
(703) 684-5968 (fax)
http://www.actwin.com/pfalzgrat/nmha.html
1,2,3,4,5,6,9

MENTAL ILLNESS/MENTAL RETARDATION

See: Mental Retardation/Mental Illness

MENTAL RETARDATION

Canadian Association for Community Living
4700 Keele St
Kinsman Bldg, York University
North York, ON CAN M3J 1P3
(416) 661-9611
(416) 661-2023 (TTY)
(416) 661-5701 (fax)
1,2,4,5,6,7; French materials

People First International
PO Box 12642
Salem, OR 97309
(503) 362-0336
(503) 585-0287 (fax)
1,2,4,5,6,7; leadership/self-advocacy training

The Arc
500 E Border St, Ste 300
PO Box 1047
Arlington, TX 76010
(800) 433-5255
(817) 261-6003
(817) 277-0553 (TTY)
(817) 277-3491 (fax)
thearc@metronet.com
1,2,4,5,6; Spanish materials

Voice of the Retarded
5005 Newport Dr, Ste 108
Rolling Meadows, IL 60008
(708) 253-6020
(708) 253-6054 (fax)
1,2,3,4,6,7,9

MENTAL RETARDATION/MENTAL ILLNESS

See also: Mental Illness; Mental Retardation

National Association of the Dually Diagnosed (NADD)
110 Prince St
Kingston, NY 12401
(800) 331-5362
(914) 331-4336
(914) 331-4569 (fax)
1,2,3,4,5,6,7; regional conferences

MERRF SYNDROME

See: Myoclonus; Mitochondrial Disorders

METABOLIC DISORDERS

See also: Acidemia, Organic; Galactosemia; Lactic Acidosis; Maple Syrup Urine Disease; Niemann-Pick Disease; Phenylketonuria (PKU)

Association for Neurometabolic Disorders
5223 Brookfield Ln
Sylvania, OH 43560-1809
(419) 885-1497
1,3,4,6,9

Canadian Society for Metabolic Disease
5301 Ranger Ave
N Vancouver, BC CAN V7R 3M7
(604) 986-2509
(604) 293-7126 (fax)
1,2,3,4,6,8,9

Metabolic Information Network
PO Box 670847
Dallas , TX 75367-0847
(800) 945-2188
(214) 696-2188
(800) 955-3258 (fax)
(214) 696-3258 (fax)
mizesg@ix.netcom.com
1,2,4,6,9

The World Life Foundation
PO Box 571
Bedford, TX 76095
(800) 289-5433
(817) 285-0216 (fax)
3; financial assistance for treatment-related travel expenses

METACHROMATIC LEUKODYSTROPHY

See: Leukodystrophy; Tay-Sachs Disease

METAPHYSEAL DYSOSTOSIS, TYPE B IV

See: Shwachman Syndrome

METATROPHIC DYSPLASIA

See: Dwarfism, Metatrophic

METHYLMALONIC ACIDEMIA

See: Acidemia, Organic

MICROPHTHALMIA

See: Anophthalmia; Visual Impairments

MICROSOMIA, HEMIFACIAL

See: Craniofacial Disorders; Goldenhar Syndrome

MICROTIA

See also: Craniofacial Disorders

Microtia-Atresia Support Group
c/o Jack Gross
330 7th Ave, #1203
New York, NY 10001
(212) 947-0770
(212) 714-1224 (fax)
3,4

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

MIKAELIAN SYNDROME

See: Ectodermal Dysplasias

MILLER SYNDROME

See: Nager & Miller Syndromes

MILLER-DIEKER SYNDROME

See: Lissencephaly

MILLER-FISCHER SYNDROME

See: Guillain-Barre Syndrome

MILROY DISEASE

See: Lymphatic Malformations; Lymphedema

MITOCHONDRIAL DISORDERS

COX Foundation for All Mitochondrial Diseases
PO Box 1151
Monroeville, PA 15146-1151
(412) 856-1297 (voice/fax)
✉ 74743.2705@compuserve.com
1,2,3

Mitochondrial Disorders Foundation of America
5100-1B Clayton Rd, Ste 187
Concord, CA 94521
(510) 798-8798 (voice/fax)
✉ 102125.1233@compuserve.com
1,2,3,4,5,8,9

MITOCHONDRIAL MYOPATHY

See: Mitochondrial Disorders; Muscular Dystrophy

MOEBIUS SYNDROME

See also: Craniofacial Disorders; Limb Disorders

Moebius Syndrome Support Group
39521 Rowen Ct
Palmdale, CA 93551
(805) 267-2570
(310) 470-2000
(914) 834-6008
1,2,3,6,8,9

MONOSOMY X

See: Turner Syndrome

MORQUIO SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

MORVAN DISEASE

See: Syringomyelia

MOTOR-SENSORY NEUROPATHY, HEREDITARY

See: Charcot-Marie-Tooth Disease

MOYAMOYA DISEASE

See also: Stroke; Vascular Malformations

Families with Moyamoya Network
c/o Dawn Gruettner
4900 McGowan St SE
Cedar Rapids, IA 52403
(800) 261-6692
2,3

MUCOLIPIDOSES

See: Mucopolysaccharidosis; Mucolipidosis Type IV; Tay-Sachs Disease

MUCOLIPIDOSIS TYPE IV

See also: Mucopolysaccharidosis; Tay-Sachs Disease; Visual Impairments

ML4 Foundation
6 Concord Dr
Monsey, NY 10952
(914) 425-0639
(914) 425-4205 (fax)
3,4,8,9

MUCOPOLYSACCHARIDOSIS

See also: Metabolic Disorders; Tay-Sachs Disease

National Mucopolysaccharidosis Society
17 Kraemer St
Hicksville, NY 11801
(516) 931-6338
1,2,3,4,5,6,8,9; Spanish materials

MUCOSULFATIDOSIS

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

MUENCHMEYER SYNDROME

See: Fibrodysplasia Ossificans Progressiva

MULTIPLE CARBOXYLASE DEFICIENCY

See: Metabolic Disorders

MULTIPLE CARTILAGNOUS ENCHONDROSES

See: Ollier Disease

MULTIPLE ENDOCRINE NEOPLASIA I

See also: Adrenal Disorders; Diabetes Mellitus; Thyroid Disorders

Multiple Endocrine Neoplasia I
c/o Mrs Cathy McMillan
Box 100
Meota, SK CAN S0M 1X0
(306) 892-2080
1,3,5,6,9

MULTIPLE SCLEROSIS

Multiple Sclerosis Society of Canada
250 Bloor St E, Ste 1000
Toronto, ON CAN M4W 3P9
(800) 268-7582 (Canada only)
(416) 922-6065
(416) 922-7538 (fax)
✉ info@mssoc.ca
1,2,4,6,7,8,

National Multiple Sclerosis Society
733 3rd Ave, 6th Fl
New York, NY 10017
(800) 344-4867
(212) 986-3240
(212) 986-7981 (fax)
✉ nat@nmss.org
1,2,3,4,5,6,7,8,9

MULTIPLE SULFATASE DEFICIENCY

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

MUSCLE PHOSPHOFRUCTOKINASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCLE PHOSPHORYLASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

MUSCULAR ATROPHY, PERONEAL

See: Charcot-Marie-Tooth Disease

MUSCULAR DYSTROPHY

See also: Facio-Scapulo-Humeral Muscular Dystrophy; Ventilator Use

Muscular Dystrophy Association
3300 E Sunrise Dr
Tucson, AZ 85718-3208
(800) 572-1717
(520) 529-2000
(520) 529-5300 (fax)
✉ 74431.2513@compuserve.com
1,2,3,4,5,8; Spanish materials, local clinics, financial assistance for wheelchair purchases, summer camps

Muscular Dystrophy Association of Canada
2345 Yonge St, Ste 900
Toronto, ON CAN M4P 2E5
(800) 567-2873 (Canada only)
(416) 488-0030
(416) 488-7523 (voice/fax)
1,2,3,4,5,6,8,9; French materials

Society for Muscular Dystrophy Information International
PO Box 479
Bridgewater, NS CAN B4V 2X6
(902) 682-3086
(902) 682-3142 (fax)
1,2,4

MUSCULAR DYSTROPHY, DEJERINE-LANDOUZY

See: Facio-Scapulo-Humeral Muscular Dystrophy

MUSCULAR DYSTROPHY, FACIO-SCAPULO-HUMERAL

See: Facio-Scapulo-Humeral Muscular Dystrophy

MYASTHENIA GRAVIS

See also: Muscular Dystrophy

Myasthenia Gravis
25 Caravan Dr
Don Mills, ON CAN M3B 1M9
(416) 444-8357
1,2,5,8,9

Myasthenia Gravis Foundation of America
222 S Riverside Plaza, Ste 1540
Chicago, IL 60606
(800) 541-5454
(312) 258-0461 (fax)
2,3,4,5,6,7,8,9; Spanish materials

MYASTHENIC SYNDROME OF LAMBERT-EATON

See: Muscular Dystrophy

MYELIN DISORDERS

See also: Leukodystrophy; Myelin, Insufficient

The Myelin Project
1747 Pennsylvania Ave NW
Ste 950
Washington, DC 20006
(202) 452-8994
(202) 785-9578 (fax)
✉ myelin@tmn.com
http://www.myelin.org/
1,2,4,8; Italian/French/German materials

The Myelin Project of Canada
c/o Julie and Wayne Simmons
4330 Spinningdale Ct
Mississauga, ON CAN L5M 3J8
(905) 567-8843
(905) 567-9189 (fax)
2,6,7,8,9

MYELIN, INSUFFICIENT

See also: Myelin Disorders

Myelin Messenger Newsletter
c/o Ruth Anderson
HC-29, Box 686
Stable Ln
Prescott, AZ 86301-7435
(520) 776-7556
1,3,7,9

MYELODYSPLASIA

See: Anemia, Aplastic

MYELOMA

See also: Cancer; Leukemia

International Myeloma Foundation
2120 Stanley Hills Dr
Los Angeles, CA 90046
(800) 452-2873
(213) 654-3023
(213) 656-1182 (fax)
1,2,3,4,6,7,8

MYELOMA, MULTIPLE

See: Myeloma

MYELOSYRINGOSIS

See: Syringomyelia

MYOADENYLATE DEAMINASE DEFICIENCY

See: Muscular Dystrophy

MYOCLONUS

See also: Epilepsy; Opsoclonus-Myoclonus Syndrome

Moving Forward
2934 Glenmore Ave
Kettering, OH 45409
(513) 293-0409
2,4,7

Myoclonus Families United
1553 E 35th St
Brooklyn, NY 11234
(718) 252-2133
3,4

MYODENYLATE DEAMINASE DEFICIENCY

See: Muscular Dystrophy

MYOPATHIES, CONGENITAL

See: Myotubular Myopathy; X-Linked

MYOPATHY, CENTRONUCLEAR

See: Myotubular Myopathy, X-Linked; Muscular Dystrophy

MYOPATHY, HYPERTHYROID

See: Muscular Dystrophy; Thyroid Disorders

MYOPATHY, HYPOTHYROID

See: Muscular Dystrophy; Thyroid Disorders

Eight-month-old **Brandon Bo** doesn't let anything bother l especially when he is relaxing o couch. Now 2, Brandon lives in Scarborough, Ontario, Canada w his parents, Dorothy and Kevin, his little brother Mathew, 7 mor Brandon, who has cerebral pals enjoys reading and music. His m describes him as "a great keybo player!"

MYOPHOSPHORYLASE DEFICIENCY
See: Glycogen Storage Diseases

MYOSITIS
See also: Autoimmune Disorders

National Myositis Association
7720B El Camino Real, Ste 367
Rancho La Costa, CA 92009
(800) 230-0441
(619) 436-2185
1,2,3,4,5,9

MYOSITIS OSSIFICANS
See: Fibrodysplasia Ossificans Progressiva

MYOTONIA, CONGENITA
See: Muscular Dystrophy

MYOTUBULAR MYOPATHY, X-LINKED
See also: Muscular Dystrophy

X-Linked Myotubular Myopathy Resource Group
2413 Quaker Dr
Texas City, TX 77590
(409) 945-8569
gscoggin@aol.com
1,2,3,9

MYXEDEMA
See: Thyroid Disorders

N-ACETYL GLUTAMATE SYNTHETASE (NAGS) DEFICIENCY
See: Urea Cycle Disorders

NAEGELI-FRANCESCHETTI-JADASSOHN SYNDROME
See: Ectodermal Dysplasias; Incontinentia Pigmenti

NAGER & MILLER SYNDROMES
See also: Craniofacial Disorders; Hearing Impairments; Limb Disorders

Foundation for Nager and Miller Syndromes (FNMS)
333 Country Ln
Glenview, IL 60025-5104
(800) 507-3667
(708) 724-6449 (voice/fax)
1,2,3,4,6,8,9

NASAL ENCEPHALOCELE
See: Craniofacial Disorders

NEMALINE MYOPATHY
See: Muscular Dystrophy

NEONATAL ILLNESS/PREMATURITY
See also: Intraventricular Hemorrhage; Retinopathy of Prematurity

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913
(317) 872-0795 (fax)
1,2,3,4,6

NEPHRITIS
See: Kidney Diseases, Hereditary

NEUROFIBROMATOSIS
See also: Acoustic Neuroma; Hearing Impairments; Neurofibromatosis, Type 2; Visual Impairments

National Neurofibromatosis Foundation
95 Pine St, 16th Fl
New York, NY 10005
(800) 323-7938 (V/TTY)
(212) 344-6633
(212) 747-0004 (fax)
nnff@aol.com
http://nf.org/
1,2,4,5,6,8,9; Spanish/French/Chinese/Arabic/Italian/Vietnamese/Turkish/Greek materials

Neurofibromatosis, Inc
8855 Annapolis, Ste 110
Lanham, MD 20706-2924
(800) 942-6825
(301) 577-8984
(410) 461-5213 (TTY)
(301) 577-0016 (fax)
1,2,3,4,5,7,8

Neurofibromatosis Society of Ontario
923 Annes St
Whitby, ON CAN L1N 5K7
(905) 430-6141 (voice/fax)
1,2,4,6,8

NEUROFIBROMATOSIS, TYPE 2
See also: Acoustic Neuroma; Hearing Impairments; Neurofibromatosis; Visual Impairments

NF-2 Sharing Network
10074 Cabachon Ct
Ellicott City, MD 21042-6202
(410) 461-2245 (voice/fax)
(410) 461-5213 (TTY)
1,2,3,4,6,9

NEUROMETABOLIC DISORDERS
See: Metabolic Disorders

NEURONAL CEROID LIPOFUSCINOSES
See: Batten Disease

NEUROPATHY, HEREDITARY, SENSORY MOTOR
See: Charcot-Marie-Tooth Disease

NEUROPATHY, PERIPHERAL
See: Charcot-Marie-Tooth Disease

NEUTROPENIA

National Neutropenia Network
PO Box 205
6348 N Milwaukee Ave
Chicago, IL 60646
(800) 638-8768
(201) 361-9448
(201) 361-8734 (fax)
1,2,3,4,7,8,9

Neutropenia Support Association
PO Box 243, 905 Corydon Ave
Winnipeg, MB CAN R3M 3S7
(800) 663-8876
(204) 489-8454
carlsonm@neutropenia.ca
1,2,3,4,5,6,7,8,9; speakers bureau

Severe Chronic Neutropenia International Registry
Puget Sound Plaza, #1365
1325 4th Ave
Seattle, WA 98101-2509
(800) 726-4463
(206) 543-9749
(206) 543-3668 (fax)
1,2,4,9

NEUTROPENIA-PANCREATIC INSUFFICIENCY
See: Shwachman Syndrome

NEVI, GIANT CONGENITAL
See also: Craniofacial Disorders; Hemangioma; Ichthyosis; Klippel-Trenaunay Syndrome; Sturge-Weber Syndrome; Vascular Malformations

Nevus Network
2585 Treehouse Dr
Lake Ridge, VA 22192-1310
(703) 492-0253
1,3,4,8,9; Spanish materials

NEVILLE DISEASE
See: Niemann-Pick Disease

NIEMANN-PICK DISEASE
See also: Ataxia; Metabolic Disorders; Tay-Sachs Disease

National Niemann-Pick Disease Foundation
22201 Riverpoint Trail
Carrollton, VA 23314
(804) 357-6774
1,2,3,4,6,7,8,9; French/German materials

NONKETOTIC HYPERGLYCINEMIA
See: Acidemia, Organic

NONNE-MILROY-MEIGE SYNDROME
See: Lymphatic Malformations; Lymphedema

NOONAN SYNDROME
See also: Cardio-Facio-Cutaneous Syndrome; Growth Disorders; Heart Disorders; Malignant Hyperthermia; Williams Syndrome

Noonan Syndrome Society
c/o Susan Espinoza
128 Pine Ave
San Jose, CA 95125
(408) 723-5188
1,2,3,4,6,7,9

NORMAN-ROBERTS SYNDROME
See: Lissencephaly

NORRIE DISEASE
See also: Hearing Impairments; Visual Impairments

Norrie Disease Foundation
Developmental Neurogenetics Unit
Mass General Hospital
E Rm 6217
149 13 St
Charlestown, MA 02129
(617) 726-5718
(617) 724-9620 (fax)
sims@helix.mgh.harvard.edu
http://neuro-www.mgh.harvard.edu/mecbio.html
3,4,9; DNA diagnostic lab

NYHAN SYNDROME
See: Lesch-Nyhan Syndrome

OAV SYNDROME
See: Goldenhar Syndrome

OBSESSIVE-COMPULSIVE DISORDER

OC Foundation
PO Box 70
Milford, CT 06460
(203) 878-5669
(203) 874-2826 (fax)
jphs28a@prodigy.com
1,2,3,4,5,6,7,8

OBSTRUCTIVE HYDROCEPHALUS
See: Dandy-Walker Syndrome

OCULO-AURICULO-VERTEBRAL SPECTUM
See: Goldenhar Syndrome

OCULOCEREBRORENAL SYNDROME
See: Lowe Syndrome

OCULODENTODIGITAL SYNDROME; TYPES I & II
See: Ectodermal Dysplasias

OCULOOSTEOCUTANEOUS SYNDROME
See: Ectodermal Dysplasias

ODONTOONYCHODERMAL DYSPLASIA
See: Ectodermal Dysplasias

ODONTOONYCHOHYPO-HIDROTIC DYSPLASIA
See: Ectodermal Dysplasias

ODONTOTRICHODYSPLASIA WITH NEUTROPENIA
See: Ectodermal Dysplasias; Neutropenia

ODONTOTRICHOMELIC SYNDROME
See: Ectodermal Dysplasias

OLDFIELD SYNDROME
See: Peutz-Jeghers Syndrome; Polyposis

OLIGOPHRENIA-MICROPHTHALMOS
See: Norrie Disease

OLIGOSACCHARIDOSES
See: Tay-Sachs Disease

OLLIER DISEASE
See also: Growth Disorders

Ollier's Disease Self Help Group
PO Box 52616
Shaw AFB, SC 29152-1521
(803) 775-1757
1,3,4

ONDINE'S CURSE
See: Central Hypoventilation Syndrome, Congenital

OPHTHALMOARTHROPATHY
See: Stickler Syndrome

OPITZ HYPERTELORISM-HYPOSPADIUS SYNDROME
See: Opitz Syndrome

OPITZ OCULOGENITOLARYNGEAL SYNDROME
See: Opitz Syndrome

OPITZ SYNDROME

International Optiz-Frias Syndrome Association
116 June Ave
Nanaimo, BC CAN V9S 4R7
(604) 754-7088
(604) 754-4536 (fax)
3,4,9

Opitz Family Network
PO Box 516
Grand Lake, CO 80447
(970) 627-8935
(970) 627-8935 (fax)
1,2,3,9; Spanish/German materials

OPITZ-BBBG COMPOUND SYNDROME
See: Opitz Syndrome

OPITZ-FRIAS SYNDROME
See: Opitz Syndrome

OPSOCLONUS-MYOCLONUS SYNDROME
See also: Epilepsy; Myoclonus

Opsoclonus-Myoclonus Parent-Talk Support Network
c/o Connie Quinn
725 North St
Jim Thorpe, PA 18229
(717) 325-3302
1,3

OPTIC NERVE HYPOPLASIA
See: Septo-Optic Dysplasia

ORBITAL HYPERTELORISM
See: Craniofacial Disorders

ORGANIC ACIDEMIA
See: Acidemia, Organic

ORNITHINE TRANSCARBAMYLASE (OTC) DEFICIENCY

See: Urea Cycle Disorders

OROFACIODIGITAL SYNDROME, TYPE I

See: Ectodermal Dysplasias

OSLER-WEBER-RENDU SYNDROME

See: Hemorrhagic Telangiectasis, Hereditary

OSTEITIS FIBROSA DISSEMINATA

See: McCune-Albright Syndrome

OSTEOCHONDROMATOSIS

See: Exostoses, Multiple Hereditary

OSTEOGENESIS IMPERFECTA

See also: Growth Disorders

Canadian Osteogenesis Imperfecta Society
128 Thornhill Crescent
Chatham, ON CAN N7L 4M3
(519) 436-0025
(519) 351-4043 (fax)
1,2,3,6

Osteogenesis Imperfecta Foundation
5005 W Laurel St, Ste 210
Tampa, FL 33607
(800) 981-2663
(813) 282-1161
(813) 287-8214 (fax)
boneink@aol.com
1,2,3,4,5,6,7,8,9

OSTOMY

United Ostomy Association
36 Executive Pk, Ste 120
Irvine, CA 92714-6744
(800) 826-0826
(714) 660-8624
(714) 660-9262 (fax)
1,2,4,5,7

United Ostomy Association of Canada
PO Box 46057
College Park PO
444 Yonge St
Toronto, ON CAN M5B 2L8
(416) 595-5452
(416) 595-9924 (fax)
1,2,3,4,5,6,7,9; youth network

OXALOSIS & HYPEROXALURIA

See also: Kidney Disorders

Oxalosis & Hyperoxaluria Foundation
37R Thompson St
Maynard, MA 01754
(800) 484-5031, ext 5100
(508) 461-0614 (voice/fax)
oht@oht.ultranet.com
http://www.ultranet.com/~oht/
1,2,3,4,8

OXOPROLINURIA

See: Acidemia, Organic

PACHYGYRIA

See: Lissencephaly

PACHYONYCHIA, CONGENITAL

See: Ectodermal Dysplasias

PAGON SYNDROME

See: Hydrocephalus, Lissencephaly

PALLISTER MOSAIC ANEUPLOIDY

See: Pallister-Killian Syndrome

PALLISTER MOSAIC SYNDROME

See: Pallister-Killian Syndrome

PALLISTER-HALL SYNDROME

See also: Anorectal Malformations; Pituitary Disorders

Pallister-Hall Foundation
RFD Box 3000, Fairground Rd
Bradford, VT 05033
(802) 222-9683
2,3,4,9

PALLISTER-KILLIAN SYNDROME

See also: Epilepsy

Pallister-Killian Family Support Network
3700 Wyndale Ct
Ft Worth, TX 76109
(817) 927-8854
(817) 927-2073 (fax)
3

PALMOPLANTAR HYPERKERATOSIS AND ALOPECIA

See: Ectodermal Dysplasias

PANCREATIC INSUFFICIENCY WITH NEUTROPENIA

See: Shwachman Syndrome

PANCYTOPENIA, CONGENITAL

See: Anemia, Fanconi

PANHYPOPITUITARISM

See: Growth Disorders

PANMYELOPATHY

See: Anemia, Aplastic

PANMYELOPHTHISIS

See: Anemia, Aplastic

PAPILLOMAS

See: Respiratory Papillomatosis, Recurrent

PAPILLON-LEFEVRE SYNDROME

See: Ectodermal Dysplasias

PARALYSIS, PERIODIC

See: Muscular Dystrophy

PARAMYOTONIA CONGENITA

See: Muscular Dystrophy

PARKES-WEBER SYNDROME

See: Klippel-Trenaunay Syndrome

PARRY-ROMBERG SYNDROME

See: Craniofacial Disorders

PATIN SYNDROME

See: Fibrodysplasia Ossificans Progressiva

PDD

See: Autism

PELIZAEUS-MERZBACHER DISEASE

See: Leukodystrophy

PEMPHIGUS, FAMILIAL

See: Ichthyosis

PEPCK DEFICIENCY

See: Lactic Acidosis; Mitochondrial Disorders

PERIPHERAL NEUROPATHY

See: Charcot-Marie-Tooth Disease

PERONEAL MUSCULAR ATROPHY

See: Charcot-Marie-Tooth Disease

PERVASIVE DEVELOPMENTAL DISORDER (PDD)

See: Autism

PEUTZ-JEGHERS SYNDROME

See also: Polyposis

Hereditary Colon Cancer Registry
c/o Jill D. Brensinger
Johns Hopkins Hospital
550 N Broadway, Ste 108
Baltimore, MD 21205
(410) 614-4038
(410) 614-9544 (fax)
brensjr@wpmail.onc.jhu.edu
2,3,4,8,9

PEUTZ-TOURAINE SYNDROME

See: Peutz-Jeghers Syndrome; Polyposis

PFEIFFER SYNDROME

See: Craniofacial Disorders

PHAKOMATOSIS

See: Tuberous Sclerosis

PHENYLKETONURIA (PKU)

See also: Metabolic Disorders

Children's PKU Network
8388 Vickers St, Ste 113
San Diego, CA 92111
(619) 569-9881
(619) 292-6231 (fax)
1,2,3,4,9; Spanish materials

National PKU News
c/o Virginia Schuett
6869 Woodlawn Ave NE, Ste 116
Seattle, WA 98115-5469
(206) 525-8140
(206) 525-5023 (fax)
http://www.wolfenet.com/~kronmal
1,2,3

PKU Canada Family Association
c/o Hospital for Sick Children
555 University Ave
Toronto, ON CAN M5G 1X8
(416) 813-6356
(416) 813-5345 (fax)
3,4

PHOSPHOENOLPYRUVATE CARBOXYKINASE DEFICIENCY

See: Lactic Acidosis; Mitochondrial Disorders

PHOSPHOFRUCTOKINASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

PHOSPHOGLYCERATE KINASE DEFICIENCY

See: Muscular Dystrophy

PHOSPHOGLYCERATE MUTASE DEFICIENCY

See: Muscular Dystrophy

PHOSPHORYLASE B KINASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

PHOSPHORYLASE DEFICIENCY

See: Glycogen Storage Diseases; Muscular Dystrophy

PIERRE ROBIN SYNDROME

See: Craniofacial Disorders; Growth Disorders

PIGMENT DISORDERS

See: Albinism & Hypopigmentation; Vitiligo

PILI TORTI AND ENAMEL HYPOPLASIA

See: Ectodermal Dysplasias

PILI TORTI AND ONYCHODYSPLASIA

See: Ectodermal Dysplasias

PITUITARY DISORDERS

See also: Pituitary Tumors

Brain and Pituitary Foundation of America
281 E Moody Ave
Fresno, CA 93720-1524
(209) 434-0610
2,3,4,9

PITUITARY TUMORS

See also: Pituitary Disorders

Pituitary Tumor Network Association
16350 Ventura Blvd, Ste 231
Encino, CA 91436
(800) 642-9211
(918) 834-5191
(805) 499-1523 (fax)
1,2,3,4,5,6,7,8; summer camp

KEY TO SERVICES

1. Periodical/newsletter
2. Informational materials
3. Networking/matching
4. Referrals to local resources
5. Local chapters
6. National conferences
7. National advocacy efforts
8. Fund research
9. Maintain research registry

Pituitary Tumor Network Association of Canada
59 Lanyard Rd
Weston, ONT CAN M9M 1Y8
(416) 749-4992
1,2,3,4,6,8

PITYRIASIS RUBRA PILARIS

See: Ichthyosis

POLIO

International Polio Network
4207 Lindell Blvd, #110
St Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
1,2,3,4,6

POLYCYSTIC KIDNEY DISEASE

See: Kidney Disorders

POLYENDOCRINE ADENOMATOSIS

See: Multiple Endocrine Neoplasia I

POLYMYOSITIS

See: Muscular Dystrophy; Myositi

POLYNEURITIS, ACUTE IDIOPATHIC

See: Guillain-Barre Syndrome

POLYNEUROPATHY, CHRONIC RELAPSING

See: Guillain-Barre Syndrome

POLYOSTOTIC FIBROUS DYSPLASIA

See: McCune-Albright Syndrome

POLYPOSIS

See also: Cancer; Peutz-Jeghers Syndrome

Familial Gastrointestinal Cancer Registry
Mount Sinai Hospital
600 University Ave, Ste 1157
Toronto, ON CAN M5G 1X5
(416) 586-8334
(416) 586-8644 (fax)
gicanreg@mshri.on.ca
1,2,3,4,7,9; genetic counseling, predictive testing; French materia

Intestinal Multiple Polyposis and Colorectal Cancer
c/o Ann Fagan
Reese's Crest, PO Box 11
Conyngham, PA 18219
(717) 788-1818
(717) 788-3712
(717) 788-4046 (fax)
user291524@aol.com
2,3,4,9

POLYRADICULONEUROPATHY

See: Guillain-Barre Syndrome

POMPE DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy; Tay-Sachs Disease

PORPHYRIA

See also: Metabolic Disorders

American Porphyria Foundation
PO Box 22712
Houston, TX 77227
(713) 266-9617
1,2,3,4,6,7,8,9

Canadian Porphyria Foundation
Box 1206
Neepawa, MB CAN R0J 1H0
(204) 476-2800
1,2,3,7; French materials

POSTAXIAL ACROFACIAL DYSOSTOSIS

See: Nager & Miller Syndromes

PRADER-WILLI SYNDROME

Ontario Prader-Willi Syndrome Association
1910 Yonge St, 4th Fl
Toronto, ON CAN M4S 3B2
(800) 563-1123
(416) 481-8657 (voice/fax)
1,2,3,4,5,6,7,8,9; French materials

Prader-Willi Foundation
223 Main St
Port Washington, NY 11050
(800) 253-7993
(516) 944-3173 (fax)
visink@pipeline.com
2,3,7,8

Prader-Willi Syndrome Association
2510 S Brentwood Blvd, Ste 220
St Louis, MO 63144
(800) 926-4797
(314) 962-7869 (fax)
1,2,3,4,5,6,7,8,9

Prader-Willi Syndrome International Information Forum
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682
(516) 484-7154 (fax)
pwsforum@aol.com
1,2,3,4,6

PREMATURITY

See: Neonatal Illness:Prematurity

PROGERIA

International Progeria Registry
c/o W. Ted Brown, MD, PhD
NY State Inst. for Basic Research in Developmental Disabilities
1050 Forest Hill Rd
Staten Island, NY 10314
(718) 494-5333
(718) 494-1026 (fax)
2,3,4,9

PROGRESSIVE HYPOERYTHEMIA

See: Anemia, Aplastic

PROGRESSIVE OSSEOUS HETEROPLASIA

See: Connective Tissue Disorders; Fibrodysplasia Ossificans Progressiva

PROPINONYL-COA CARBOXYLASE (PCC) DEFICIENCY

See: Acidemia, Organic

PROPIONIC ACIDEMIA

See: Acidemia, Organic

PROTEUS SYNDROME

See: Neurohbromatosis

PROTOCOPROPORPHYRIA

See: Liver Disorders; Porphyria

PROTOPORPHYRIA

See: Liver Disorders; Porphyria

PRUNE BELLY SYNDROME

Prune Belly Syndrome Network
1005 E Carver Rd
Tempe, AZ 85284
(602) 838-9006 (voice/fax)
3,4,9

PSEUDO-HURLER POLYDYSTROPHY

See: Mucopolysaccharidosis; Tay-Sachs Disease

PSEUDOCHOLINESTERASE DEFICIENCY

See: Malignant Hyperthermia

PSEUDOXANTHOMA ELASTICUM (PXE)

See also: Connective Tissue Disorders; Heart Disorders; Macular Diseases; Visual Impairments

National Association for Pseudoxanthoma Elasticum
1420 Ogden St
Denver, CO 80218-1910
(303) 832-5055
1,2,3,4,5,6,9

PSORIASIS

Canadian Psoriasis Foundation
1306 Wellington St, Ste 500A
Ottawa, ON CAN K1Y 3B2
(800) 265-0926 (Canada only)
(613) 728-4000
(613) 728-8913 (fax)
1,2,4,5,6; French materials

National Psoriasis Foundation
6600 SW 92nd, Ste 300
Portland, OR 97223
(503) 244-7404
(503) 245-0626 (fax)
76135.2746@compuserve.com
1,2,3,4,7,8,9; Spanish materials

PTOSIS

See: Blepharophimosis, Ptosis, Epicanthus Inversus Syndrome (BPES)

PULMONARY VALVULAR STENOSIS

See: Heart Disorders

PURINE METABOLIC DISORDERS

Purine Research Society
5424 Beech Ave
Bethesda, MD 20814
(301) 530-0354
2,3,8

PURPURA HEMORRHAGICA

See: Purpura, Idiopathic Thrombocytopenia (ITP)

PURPURA, IDIOPATHIC THROMBOCYTOPENIA (ITP)

ITP Society
Children's Blood Foundation
333 E 38th St
New York, NY 10016
(800) 487-7010
(212) 297-4340
1,2,3,4,7,8,9

PYRIMIDINE METABOLIC DISORDERS

See: Purine Metabolic Disorders

PYROGLUTAMICACIDURIA

See: Acidemia, Organic

PYRROLORPHYRIA

See: Porphyria

PYRUVATE CARBOXYLASE DEFICIENCY

See: Acidemia, Organic; Lactic Acidosis; Leigh Disease

PYRUVATE DEHYDROGENASE DEFICIENCY

See: Acidemia, Organic; Lactic Acidosis; Leigh Disease

PYRUVATE DEHYDROGENASE PHOSPHATASE

See: Lactic Acidosis; Leigh Disease

Q-T PROLONGATION

See: Long Q-T Syndrome

RAPP-HODGKINS SYNDROME

See: Cleft Palate; Craniofacial Disorders; Deaf-Blind; Ectodermal Dysplasias; Hearing Impairments; Visual Impairments

RASMUSSEN ENCEPHALITIS

See: Rasmussen Syndrome

RASMUSSEN SYNDROME

See also: Epilepsy; Seizure Disorders

Rasmussen Syndrome Support Group
c/o Al and Lynn Miller
8235 Lethbridge Rd
Millersville, MD 21108
(410) 987-5221 (voice/fax)
2,3,6,9

RECKLINGHAUSEN DISEASE

See: Neurohbromatosis

REFLEX SYMPATHETIC DYSTROPHY SYNDROME

Reflex Sympathetic Dystrophy Syndrome Association of America
116 Haddon Ave, Ste D
Haddonfield, NJ 08033
(609) 795-8845 (voice/fax)
1,2,3,4,8,9

REFRACTORY ANEMIA

See: Anemia, Aplastic

REFSUM DISEASE

See: Ichthyosis; Leukodystrophy; Tay-Sachs Disease

RENAL DISORDERS

See: Kidney Disorders

RENDU-OSLER-WEBER SYNDROME

See: Hemorrhagic Telangiectasis, Hereditary

RESPIRATORY PAPILLOMATOSIS, RECURRENT

Recurrent Respiratory Papillomatosis Foundation
50 Wesleyan Dr
Hamilton, NJ 08690
(609) 890-0502
(609) 258-3943 (fax)
mstern@pucc.princeton.edu
1,2,3,4,5,6,7,8,9

RETINITIS PIGMENTOSA

See also: Macular Diseases; Stargardt Disease; Usher Syndrome; Visual Impairments

Retinitis Pigmentosa International
PO Box 900
Woodland Hills, CA 91365
(800) 344-4877
(818) 992-0500
(818) 992-3265 (fax)
1,2,4,5,7,8,9; Spanish materials

RP Research Foundation—Fighting Blindness
c/o Sharon Cole or Margo Alpert
366 Adelaide St W, Ste 704
Toronto, ON CAN M5V 1R9
(800) 461-3331 (Canada only)
(416) 598-4951
(416) 598-9763 (fax)
1,2,3,5,8

The Foundation Fighting Blindness
Executive Plz 1, Ste 800
11350 McCormick Rd
Hunt Valley, MD 21031-1041
(800) 683-5555
(800) 683-5551 (TTY)
(410) 785-1414
(410) 785-9687 (TTY)
(410) 771-9470 (fax)
1,2,4,6,8,9; young adult program, retina donor program

RETINOBLASTOMA

See also: Cancer; Visual Impairments

National Retinoblastoma Parent Group
110 Allen Rd
Bow, NH 03304
(603) 224-4085
1,2,3,4,6,9

Retinoblastoma Family Association
14 Annette Gate
Richmond Hill, ON CAN L4C 5P3
(905) 737-2788
(905) 669-6124 (fax)
1,2,3,4,6,9; French materials, financial assistance for treatment-related transportation costs

RETINOCEREBRAL ANGIOMATOSIS

See: Von Hippel-Lindau Syndrome

RETINOPATHY OF PREMATURITY (ROP)

See also: Neonatal Illness:Prematurity; Visual Impairments

Prevent Blindness in Premature Babies
PO Box 44792
Madison, WI 53744-4792
2,3,4,9

RETT SYNDROME

Canadian Rett Syndrome Association
c/o Terry Boyd
Box 24
S Mountain, ON CAN K0E 1W0
(613) 989-2851 (voice/fax)
1,2,3,6,9; French materials

International Rett Syndrome Association
9121 Piscataway Rd, Ste 2B
Clinton, MD 20735
(800) 818-7388
(301) 856-3334
(301) 856-3336 (fax)
irsa@paltech.com
http://www.paltech.com/irsa/irsa.htm
1,2,3,4,6,7,8,9

REYE SYNDROME

See: Fatty Oxidation Disorder

RILEY-DAY SYNDROME

See: Familial Dysautonomia

RING CHROMOSOME 4

See: Chromosome Deletions; Wolf-Hirschhorn Syndrome

RING CHROMOSOME 6

See: Chromosome 6 Disorders

RING CHROMOSOME 9

See: Chromosome 9 Disorders; Chromosome Deletions; Craniofacial Disorders

RING CHROMOSOME 15

See: Chromosome 15 Disorders; Chromosome Deletions; Craniofacial Disorders; Epilepsy; Heart Disorders; Kidney Disorders; Limb Disorders; Scoliosis

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

RING CHROMOSOME 18

See: Chromosome 13 & 18 Disorders; Chromosome 18 Disorders; Chromosome Deletions; Craniofacial Disorders; Deaf-Blind; Hearing Impairments; Visual Impairments

RING CHROMOSOME 21

See: Chromosome Deletions

RING CHROMOSOME 22

See: Chromosome Deletions

ROBINOW SYNDROME

See also: Craniofacial Disorders; Short Stature

Robinow Syndrome Support Group
c/o Karla M. Kruger
15955 Uplander St NW
Andover, MN 55304-2501
(612) 434-1152
2,3,4,6

ROBINSON SYNDROME

See: Ectodermal Dysplasias

ROMANO-WARD SYNDROME

See: Long Q-T Syndrome

ROSAI-DORFMAN DISEASE

See: Histiocytosis

ROSSELI-GULIENETTI SYNDROME

See: Ectodermal Dysplasias

RSH SYNDROME

See: Smith-Lemli-Opitz Syndrome

RUBINSTEIN SYNDROME

See: Rubinstein-Taybi Syndrome

RUBINSTEIN-TAYBI SYNDROME

See also: Craniofacial Disorders; Heart Disorders

Rubinstein-Taybi Parent Group
c/o Lorne Baxter
PO Box 146
Smith Center, KS 66967
(913) 697-2984
1,2,3,7,9

RUSSELL SYNDROME

See: Russell-Silver Syndrome

RUSSELL-SILVER SYNDROME

See also: Growth Disorders; Short Stature

Russell-Silver Support Group
8500 Gigi
Newport, MI 48166
(313) 586-8038
2,3,4,5,6

SAETHRE-CHOTZEN SYNDROME

See: Craniofacial Disorders

SALAMON SYNDROME

See: Ectodermal Dysplasias

SANDHOFF DISEASE

See: Tay-Sachs Disease

SANFILIPPO SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

SCHEIE SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

SCHINZEL-GIEDION SYNDROME

See: Apnea, Sleep; Deaf-Blind; Ectodermal Dysplasias; Epilepsy; Growth Disorders; Hearing Impairments; Visual Impairments

SCID

See: Immune Disorders

SCLERODERMA

See also: Arthritis; Autoimmune Disorders

National Scleroderma Federation
Peabody Office Bldg
One Newbury St
Peabody, MA 01960
(800) 422-1113
(508) 535-6600
(508) 535-6696 (fax)
1,2,5,7,8; Spanish materials

Scleroderma Research Foundation
PO Box 200
Columbus, NJ 08022
(800) 637-4005
(609) 723-7400
(609) 723-6700 (fax)
1,2,4

United Scleroderma Foundation
PO Box 399
Watsonville, CA 95077-0399
(800) 722-4673
(408) 728-2202
(408) 728-3328 (fax)
outreach@scleroderma.com
1,2,4,5,6,7,8,9; Spanish materials

SCOLIOSIS

National Scoliosis Foundation
72 Mount Auburn St
Watertown, MA 02172
(617) 926-0397
(617) 926-0398 (fax)
scoliosis@aol.com
1,2,4,5,6; Spanish materials

SECKEL SYNDROME

See: Craniofacial Disorders; Growth Disorders

SEIZURE DISORDERS

See also: Epilepsy

THRESHOLD—Intractable Seizure Disorder Support Group & Newsletter
26 Stavola Rd
Middletown, NJ 07748-3728
(908) 957-0714
1

SENSORY AND AUTONOMIC NEUROPATHY, HEREDITARY

See: Familial Dysautonomia

SENSORY MOTOR NEUROPATHY, HEREDITARY

See: Charcot-Marie-Tooth Disease

SENSORY NEUROPATHY WITH ANHIDROSIS, CONGENITAL

See: Familial Dysautonomia

SEPTO-OPTIC DYSPLASIA

See also: Pituitary Disorders; Visual Impairments

FOCUS: For Our Children's Unique Sight
2571 Pico Pl
San Diego, CA 92109
(619) 273-1473 (voice/fax)
pilarh8826@aol.com
1,2,3,4,5,9

SERUM PROTEASE INHIBITOR DEFICIENCY

See: Alpha-1-Antitrypsin (AAT) Deficiency

SEVERE COMBINED IMMUNODEFICIENCY (SCID)

See: Immune Disorders

SEX CHROMOSOME DISORDERS, FEMALE

See: Turner Syndrome

SEX CHROMOSOME DISORDERS, MALE

See: Klinefelter Syndrome

SHORT STATURE

See also: Dwarfism; Growth Disorders

Little People of America
PO Box 9897
Washington, DC 20016
(800) 243-9273 (info line)
(301) 589-0730
1,2,3,4,5,6; Spanish materials

Little People of British Columbia
Box 4280
Vancouver, BC CAN V6B 3Z7
(604) 688-4757
1,2,3,4,6,7,9

SHPRINTZEN SYNDROME

See: DiGeorge Syndrome; Velo-Cardio-Facial Syndrome

SHWACHMAN SYNDROME

See also: Growth Disorders

Shwachman Syndrome Support Services
c/o Joan Mowery
18 Meadowlark Rd
Vernon, CT 06066
(203) 870-5454
jmowery@ntplx.net
http://open.entry.com/medical/shwach.htm
1,2,3

SHWACHMAN-DIAMOND SYNDROME

See: Shwachman Syndrome

SIALIDOSIS

See: Mucopolysaccharidosis; Tay-Sachs Disease

SIALOLIPIDOSIS

See: Mucolipidosis Type IV

SICKLE CELL ANEMIA

See: Sickle Cell Disease

SICKLE CELL DISEASE

Sickle Cell Disease Association of Piedmont
1102 E Market St
Greensboro, NC 27420-0964
(800) 733-8297
(910) 274-1507
(910) 275-7984 (fax)
1,2,4,6,7,8,9

Sickle Cell Disease Association of America
200 Corporate Pointe, Ste 495
Culver City, CA 90203-7633
(800) 421-8453
(310) 216-6363
(310) 215-3722 (fax)
1,2,4,5,6,7,8

Sickle Cell Society
6999 Cote Des Neiges, Ste 33
Montreal, PQ CAN H3S 2B8
(514) 735-5109
(514) 735-5100 (fax)
2,3,4,8,9; French materials

SIDS

See: Sudden Infant Death Syndrome (SIDS)

SILVER SYNDROME

See: Russell-Silver Syndrome

SILVER-RUSSELL SYNDROME

See: Russell-Silver Syndrome

SKELETAL DYSPLASIA

See: Dwarfism; Growth Disorders; Short Stature

SLEEP APNEA

See: Apnea, Sleep

SLO SYNDROME

See: Smith-Lemli-Opitz Syndrome

SLY SYNDROME

See: Mucopolysaccharidosis; Tay-Sachs Disease

Justin Alfred Graber, shown h at 6 months wearing his dad's favorite cap, died of pneumonia i October 1993. Justin, of Grand Prairie, Alberta, Canada, had mu disabilities including cerebral pa and hypotonia. "His short life wa filled with accomplishments that exceeded all expectations," write parents Sheldon and Marian. "H our precious gift and hero, teach us, our families and friends the meaning of love."

SMITH-LEMLI-OPITZ SYNDROME

See also: Craniofacial Disorders

Smith-Lemli-Opitz Advocacy & Exchange
222 Valley Green Dr
Aston, PA 19014
(610) 494-5287
1,2,3,6,9

SMITH-MAGENIS SYNDROME

PRISMS: Parents & Researchers Interested in Smith-Magenis Syndrome
11875 Fawn Ridge Ln
Reston, VA 22094
(703) 709-0568
acmsmith@nchgr.nih.gov
1,2,3,4,9

SOTOS SYNDROME

See also: Growth Disorders

Sotos Syndrome USA Support Association
Three Danada Sq E, #325
Wheaton, IL 60187
(708) 682-8815
ssa@well.com
1,2,3,4,6,9

SOUQUES-CHARCOT SYNDROME

See: Progeria

SOUTH AFRICAN GENETIC PORPHYRIA

See: Liver Disorders; Porphyria

SPASMODIC DYSPHONIA

See: Dystonia

SPASMODIC TORTICOLLIS

See: Dystonia

SPASMODIC WRYNECK

See: Dystonia

BEST COPY AVAILABLE

SPASTIC PARAPLEGIA, FAMILIAL

See: Ataxia

SPEECH DISORDERS

See: Aphasia; Apraxia; Language Disorders; Stuttering

SPHINGOMYELIN LIPIDOSIS

See: Niemann-Pick Disease

SPIELMEYER-VOGT DISEASE

See: Batten Disease

SPIELMEYER-VOGT-BATTEN SYNDROME

See: Batten Disease

SPINA BIFIDA

See also: Arnold-Chiari Malformation; Hydrocephalus; Incontinence; Latex Allergy

Spina Bifida Association of America
4590 MacArthur Blvd NW, #250
Washington, DC 20007-4226
(800) 621-3141
(202) 944-3285
(202) 944-3295 (fax)
spinabifda@aol.com
1,2,4,5,6,8; Spanish materials, scholarship program

Spina Bifida Association of Canada
220-388 Donald St
Winnipeg, MB CAN R3B 2J4
(800) 565-9488 (Canada only)
(204) 957-1784
(204) 957-1794 (fax)
1,2,4,5,6,7,8; French materials

SPINAL CORD INJURIES

See also: Ventilator Use

American Paralysis Association
500 Morris Ave
Springfield, NJ 07081
(800) 225-0292
(201) 379-2690
(201) 912-9433 (fax)
http://www.apa.uci.edu/paralysis
1,2,8

National Spinal Cord Injury Association
545 Concord Ave, Ste 29
Cambridge, MA 02138
(800) 962-9629 (hotline only)
(617) 441-8500
(617) 441-3449 (fax)
nscia1@eworld.com
1,3,4,5,6,9

National Spinal Cord Injury Hotline
2201 Argonne Dr
Baltimore, MD 21218
(800) 526-3456
(410) 366-2325 (fax)
2,3,4

SPINAL MUSCULAR ATROPHY

See also: Muscular Dystrophy; Ventilator Use

Families of SMA
PO Box 196
Libertyville, IL 60048-0196
(800) 886-1762
(708) 367-7623 (voice/fax)
1,2,3,4,5,6,7,8,9

SPINOCEREBELLAR ATAXIA

See: Ataxia; Friedreich Ataxia

SPLENIC ANEMIA, FAMILIAL

See: Gaucher Disease

SPONDYLOEPIPHYSEAL DYSPLASIA CONGENITA

See: Cleft Palate; Growth Disorders; Visual Impairments

SPONDYLOEPIPHYSEAL DYSPLASIA TARDA

See: Growth Disorders

SSPE

See: Subacute Sclerosing Panencephalitis

STAR PROTEIN DEFICIENCY

See: Adrenal Hyperplasia, Congenital

STARGARDT DISEASE

See also: Macular Diseases; Retinitis Pigmentosa; Visual Impairments

Stargardt International and Juvenile Macular Dystrophies
c/o Macular Degeneration Intl
2968 W Ina Rd, #106
Tucson, AZ 85741
(520) 797-2525
(520) 797-8018 (fax)
tperski@aol.com
1,2,3,4,6,9

STEELY HAIR DISEASE

See: Menkes Disease

STENGEL SYNDROME

See: Batten Disease

STENGEL-BATTEN-MAYOU-SPIELMEYER-VOGT DISEASE

See: Batten Disease

STICKLER SYNDROME

See also: Arthritis; Cleft Palate; Craniofacial Disorders; Hearing Impairments; Visual Impairments

ASSIST
21075 Gallant Fox Dr
Moreno Valley, CA 92557
(909) 788-8006
(909) 682-3746 (fax)
1,2,3,9

STROKE

See also: Aphasia, Acquired

Heart and Stroke Foundation of Canada
160 George St, Ste 200
Ottawa, ON CAN K1N 9M2
(613) 241-4361
(613) 234-3278 (fax)
2,4,5,6,7,8; French materials

National Stroke Association
8480 E Orchard Rd, Ste 1000
Englewood, CO 80111-5015
(800) 787-6537
(303) 771-1700
(303) 771-1887 (TTY)
(303) 771-1886 (fax)
1,2,4,5,6,7,8,9; Spanish/French materials

STURGE-KALISCHER-WEBER SYNDROME

See: Sturge-Weber Syndrome

STURGE-WEBER SYNDROME

See also: Craniofacial Disorders; Epilepsy; Glaucoma; Klippel-Trenaunay Syndrome; Nevi, Giant Congenital; Neurofibramatosis; Tuberous Sclerosis; Vascular Malformations; Von Hippel-Lindau Syndrome

Sturge-Weber Foundation
PO Box 418
Mount Freedom, NJ 07970
(800) 627-5482
(201) 895-4445
(201) 895-4846 (fax)
1,2,3,4,5,6,8,9

Sturge-Weber Foundation—Canada
1960 Prairie Ave
Port Coquitlam, BC CAN V3B 1V4
(604) 942-9209
(604) 942-6429 (fax)
2,3,8,9

STURGE-WEBER-DIMITRI SYNDROME

See: Sturge-Weber Syndrome

STUTTERING

National Center for Stuttering
200 E 33rd St
New York, NY 10016
(800) 221-2483
(212) 683-1372 (fax)
schwrtz@ps.nyu.edu
2,3,4,5,6,8,9

National Stuttering Project
5100 E La Palma Ave, #208
Anaheim Hills, CA 92807
(800) 364-1677
(714) 693-7554
(714) 693-7400 (fax)
nspmail@aol.com
1,2,4,5,6

Speak Easy
c/o Mike Hughes
95 Evergreen Ave
St John, NB CAN E2N 1H4
(506) 696-6799
(506) 657-1224 (fax)
1,2,4,5,6,7

Stuttering Foundation of America
PO Box 11749
Memphis, TN 38111-0749
(800) 992-9392
(901) 452-7343
(901) 452-3931 (fax)
stutterfa@aol.com
1,2,4,5; Spanish/French materials

SUBACUTE NECROTIZING ENCEPHALOPATHY

See: Leigh Disease

SUBACUTE SCLEROSING PANENCEPHALITIS

See also: Epilepsy; Visual Impairments

National Subacute Sclerosing Panencephalitis Registry
c/o Paul Dyken, Director
Institute of Research in Childhood Neurodegenerative Disorders
PO Box 70191
Mobile, AL 36610-0191
(334) 478-6424
(334) 476-8277 (fax)
2,6,9

SUCCINYLCHOLINE SENSITIVITY

See: Malignant Hyperthermia

SUDDEN INFANT DEATH SYNDROME (SIDS)

See also: Bereavement Support

Canadian Foundation for the Study of Infant Deaths
586 Eglinton Ave E, Ste 308
Toronto, ON CA M4P1P2
(800) 363-7437
(416) 488-3260
(416) 488-3864 (fax)
1,2,3,4,5,6,8,9; French materials

National Sudden Infant Death Syndrome Resource Center
2070 Chain Bridge Rd
Vienna, VA 22182
(703) 821-8955
(703) 821-2098 (fax)
1,2,4; Spanish materials

Sudden Infant Death Syndrome Alliance
1314 Bedford Ave, Ste 210
Baltimore, MD 21208
(800) 221-7437
(410) 653-8226
(410) 653-8709 (fax)
1,2,3,4,5,6,7,8; Spanish materials

SUDECK ATROPHY

See: Reflex Sympathetic Dystrophy Syndrome

SULFATIDOSIS, JUVENILE, AUSTIN TYPE

See: Hearing Impairments; Ichthyosis; Leukodystrophy; Tay-Sachs Disease

SURDICARDIAC SYNDROME

See: Hearing Impairments; Long Q-T Syndrome

SWEDISH PORPHYRIA

See: Porphyria

SYNDACTYLIC OXYCEPHALY

See: Apert Syndrome

SYRINGOBULBIA

See: Syringomyelia

SYRINGOMYELIA

See also: Arnold-Chiari Malformation

ASAP: American Syringomyelia Alliance Project
PO Box 1586
Longview, TX 75606-1586
(800) 272-7282
(903) 236-7079
(903) 757-7456 (fax)
102563.3507@compuserve.com
1,2,3,6,7,9

Canadian Syringomyelia Network
65 Huntingdale Blvd, #1607
Scarborough, ON CAN M1W 2P1
(416) 498-8097
(416) 750-8197 (fax)
1,4,6,7,8

SYSTEMIC ELASTORRHEXIS OF TOURAINE

See: Pseudoxanthoma Elasticum (PXE)

SYSTEMIC MAST CELL DISEASE

See: Mastocytosis

TANGIER DISEASE

See: Tay-Sachs Disease

TARGET CELL ANEMIA

See: Cooley Anemia

TARUI DISEASE

See: Glycogen Storage Diseases; Muscular Dystrophy

TAY SYNDROME

See: Ichthyosis

TAY-SACHS DISEASE

National Tay-Sachs and Allied Diseases Association
2001 Beacon St, Ste 204
Brookline, MA 02146
(617) 277-4463
(617) 277-0134 (fax)
1,2,3,4,5,6,7,8,9; Russian materials, provides free networking phone cards for parents of children with one of 40 related disorders

National Tay-Sachs and Allied Diseases of Ontario
512 Wicklow Rd
Burlington, ON CAN L7L 2H8
(905) 634-4101
1,2,3,4,6,7,9; French materials, provides free networking phone cards for parents of children with one of 40 related disorders

TEF

See: VATER/L Association

TESCHLER-NICOLA SYNDROME

See: Pallister-Killian Syndrome

BEST COPY AVAILABLE

Sometimes even the strongest parent

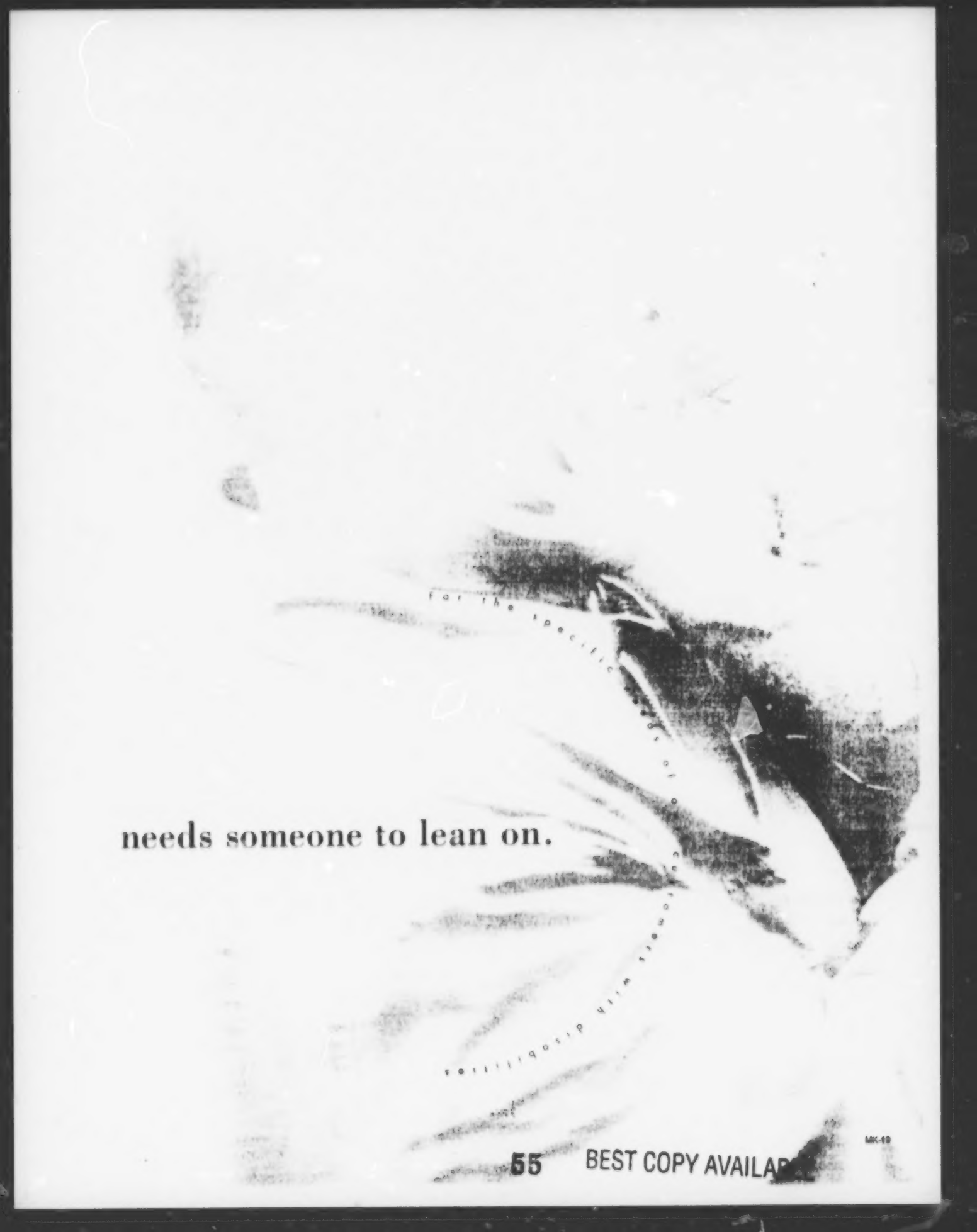
The source of a parent's strength is in the love felt for their child. At Protective Life Insurance Company, the source of our strength is in the resources we have developed since 1907. We understand the importance of caring, planning and meeting needs. That's why we offer the PROTECTIVE PROVIDER℠, a term life insurance policy developed specifically for people with disabilities. For more information on the PROTECTIVE PROVIDER℠, call 800-987-6787. At Protective Life, we're someone to lean on at a time when you need it the most.

Protective
Protective Life Insurance Company

54

Consult Policy Form TL-04 and U-573 for details, benefits and limitations. Not available in all states. If death occurs during the first two years a limited benefit will be payable in most states this benefit will be equal to all premiums paid plus interest.

Circle #226



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TESCHLER-NICOLA/KILLIAN SYNDROME

See: Pallister-Killian Syndrome

TETRASOMY 15

See: Chromosome 15 Disorders

TETROSOMY 18

See: Chromosome 13 & 18 Disorders; Chromosome 18 Disorders

THALASSEMIA MAJOR

See: Cooley Anemia

THROMBOCYTOPENIA ABSENT RADIUS (TAR) SYNDROME

See also: Heart Disorders; Kidney Disorders; Short Stature

Thrombocytopenia Absent Radius Syndrome Association
212 Sherwood Dr
Egg Harbor Twp, NJ 08234-7658
(609) 927-0418
tarsa@aol.com
1,2,3,4,9

THYROID DISORDERS

See also: Hypoparathyroidism

Thyroid Foundation of America
Ruth Sleeper Hall, #350
40 Parkman St
Boston, MA 02114-2698
(800) 832-8321
(617) 726-8500
(617) 726-4136 (fax)
1,2,4,5; Spanish materials

Thyroid Foundation of Canada
1040 Gardeners Rd, Ste C
Kingston, ON CAN K7P 1R7
(613) 634-3426
(613) 634-3483 (fax)
1,2,5,6,8; French materials

TOOTH AND NAIL SYNDROME

See: Ectodermal Dysplasias

TORSION DYSTONIA, IDIOPATHIC

See: Dystonia

TOURETTE SYNDROME

See also: Attention Deficit Disorder; Obsessive-Compulsive Disorder

Tourette Syndrome Association
42-40 Bell Blvd
Bayside, NY 11361-2820
(718) 224-2999
(718) 279-9596 (fax)
tourette@ix.netcom.com
1,2,4,6,8; Spanish materials

Tourette Syndrome Foundation of Canada
238 Davenport Rd, Box 343
Toronto, ON CAN M5R 1J6
(800) 361-3120 (Canada only)
(416) 636-2800
(416) 636-1688 (fax)
1,2,4,5,8; French materials

TOXIC PARALYTIC ANEMIA

See: Anemia, Aplastic

TRACHEOESOPHAGEAL FISTULA (TEF)

See: VATERL Association

TREACHER COLLINS SYNDROME

See also: Craniofacial Disorders; Hearing Impairments

Treacher Collins Foundation
PO Box 683
Norwich, VT 05055
(800) 823-2055
(802) 649-3050
1,2,3,4,6

TREMOR

International Tremor Foundation
333 W Washington Blvd
Chicago, IL 60607
(312) 733-1893
1,2,4,7,8,9

TRICHODENTOOSSEOUS SYNDROME; TYPES I, II & III

See: Ectodermal Dysplasias

TRICHODYSPLASIA-ONYCHOGRYPOSIS-HYPOHIDROSIS-CATARACT

See: Ectodermal Dysplasias

TRICHOFACIOHYPOHIDROTIC SYNDROME

See: Ectodermal Dysplasias

TRICHONYCHODENTAL DYSPLASIA

See: Ectodermal Dysplasias

TRICHONYCHODYSPLASIA WITH XERODERMA

See: Ectodermal Dysplasias

TRICHOOCULODERMO-VERTEBRAL SYNDROME

See: Ectodermal Dysplasias

TRICHOODONTOONYCHIAL DYSPLASIA

See: Ectodermal Dysplasias

TRICHOODONTOONYCH-HYPOHIDROTIC DYSPLASIA WITH CATARACT

See: Ectodermal Dysplasias

TRICHOODONTOONYCHO-DERMAL SYNDROME

See: Ectodermal Dysplasias

TRICHOODONTOONYCHO-DYSPLASIA WITH PILI TORTI

See: Ectodermal Dysplasias

TRICHOPOLIODYSTROPHY

See: Menkes Disease

TRICHORHINOPHALANGEAL (TRP) SYNDROME

See: Ectodermal Dysplasias

TRICHOTILLOMANIA

See: Obsessive-Compulsive Disorder

TRIPHALANGEAL THUMBS-ONYCHODYSTROPHY-DEAFNESS

See: Ectodermal Dysplasias; Hearing Impairments

TRISOMY DISORDERS

See: Chromosome 13 & 18 Disorders

TRP SYNDROME, TYPE I

See: Ectodermal Dysplasias

TUBEROUS SCLEROSIS

See also: Autism; Epilepsy; Learning Disabilities

National Tuberous Sclerosis Association
8000 Corporate Dr, Ste 120
Landover, MD 20785
(800) 225-6872
(301) 459-9888
(301) 459-0394 (fax)
ntsa@aol.com
1,2,3,4,7,8,9

Tuberous Sclerosis Canada Sclérose Tubéreuse
2443 New Wood Dr
Oakville, ON CA L6H 5Y3
(800) 347-0252
(905) 257-1997
jillian.dasilva@ablelink.org
1,2,3,4,5,7,8,9; lending library (books, videos)

TURCOT SYNDROME

See: Brain Tumors; Cancer

TURNER SYNDROME

See also: Growth Disorders

Turner's Syndrome Society—Canada
7777 Keele St, Fl 2
Concord, ON CAN L4K 1Y7
(800) 465-6744
(905) 660-7766
(905) 660-7450 (fax)
1,2,3,4,5,6,7; French materials

Turner's Syndrome Society of the US
15500 Wayzata Blvd
811 12 Oak Ctr
Wayzata, MN 55391
(612) 475-9944
(612) 475-9949 (fax)
1,2,3,5,6,7,9; Spanish materials

TWIN TO TWIN TRANSFUSION SYNDROME

Twin to Twin Transfusion Syndrome Foundation
411 Longbeach Pkwy
Bay Village, OH 44140
(216) 899-8887
(216) 401-8887 (urgent calls only)
(216) 899-1184 (fax)
tttsfound@aol.com
1,2,3,4,5,7,8,9

TYROSINEMIA, HEREDITARY, HEPATORENAL TYPE

See: Tyrosinemia I

TYROSINEMIA I

See also: Kidney Disorders; Liver Disorders

Hereditary Tyrosinemia Group—Aid Enfants Tyrosinemiques du Quebec
3162 Rue Granville
Jonquiere, PQ CAN G7S 2B9
(418) 548-1580
2,3,4,8,9; French materials

TYROSYLURIA

See: Tyrosinemia I

UREA CYCLE DISORDERS

See also: Metabolic Disorders

National Urea Cycle Disorders Foundation
PO Box 32
Sayreville, NJ 08872
(800) 386-8233
1,2,3,6,8,9

UROLOGIC DISORDERS

See: Incontinence; Kidney Diseases, Hereditary; Kidney Disorders

UROSTOMY

See: Ostomy

URTICARIA PIGMENTOSA

See: Mastocytosis

USHER SYNDROME

See also: Deaf-Blind; Hearing Impairments; Retinitis Pigmentosa; Visual Impairments

Usher Family Support
c/o Helen Anderson
4918 42nd Ave S
Minneapolis, MN 55417
(612) 724-6982
kadbmn@aol.com
1,3,4,6,7,9

VAN MEERKEREN I SYNDROME

See: Ehlers-Danlos Syndrome

VASCULAR MALFORMATIONS

See also: Arteriovenous Malformations (AVMs); Hemangioma; Hemorrhagic Telangiectasis, Hereditary; Klippel-Trenaunay Syndrome; Lymphatic Malformations; Moyamoya Disease; Nevi, Giant Congenital; Sturge-Weber Syndrome

National Vascular Malformations Foundation
8320 Nightingale
Dearborn Heights, MI 48127
(313) 274-1243 (voice/fax)
1,2,3,4,6

VATER ASSOCIATION

See: VATERL Association

KEY TO SERVICES

1 Periodical/newsletter
2 Informational materials
3 Networking/matching
4 Referrals to local resources
5 Local chapters
6 National conferences
7 National advocacy efforts
8 Fund research
9 Maintain research registry

VATERL ASSOCIATION

See also: Anorectal Malformations; CHARGE Association; Heart Disorders; Kidney Disorders; Limb Disorders; Spina Bifida

TEF/VATER Support Network
c/o Greg and Terri Burke
15301 Grey Fox Rd
Upper Marlboro, MD 20772
(301) 952-6837
1,2,3,7,8,9

VELO-CARDIO-FACIAL SYNDROME

See also: CHARGE Association; Craniofacial Disorders; DiGeorge Syndrome; Heart Disorders

Velo-Cardio-Facial Syndrome Parent Support Group
110-45 Queens Blvd
Forest Hills, NY 11375-5501
(718) 261-8049
(718) 261-7346 (fax)
2,3,4,9

VENOUS MALFORMATIONS

See: Vascular Malformations

VENTILATOR USE

Citizens for Independence in Living & Breathing
78 Golfwood Hghts
Toronto, ON CAN M9P 3M2
(416) 244-2248 (voice/fax)
2,3,4,6

International Ventilator Users Networks
4207 Lindell Blvd, #110
St Louis, MO 63108-2915
(314) 534-0475
(314) 534-5070 (fax)
1,2,3,4,6,7,9

VENTRICULAR DEFECTS

See: Heart Disorders

VERMIS CEREBELLAR AGENESIS

See: Joubert Syndrome

VESTIBULAR DISORDERS

See also: Balance Disorders & Dizziness

Vestibular Disorders Association
PO Box 4467
Portland, OR 97208-4467
(800) 837-8428
(503) 229-7705
(503) 228-8665 (TTY)
(503) 229-8064 (fax)
veda@teleport.com
http://www.teleport.com~veda
1,2,3,4,5,7,9; Spanish materials

VISUAL IMPAIRMENT/HEARING IMPAIRMENT

See: Deaf-Blind

VISUAL IMPAIRMENTS

See also: Albinism; Glaucoma; Macular Diseases; Retinitis Pigmentosa; Retinoblastoma; Retinopathy of Prematurity; Septo-Optic Dysplasia; Stargardt Disease; Usher Syndrome

American Council of the Blind
1155 15th St NW, Ste 720
Washington, DC 20005
(800) 424-8666 (3–5:30 p.m. EST)
(202) 467-5081
(202) 467-5085 (fax)
ncrabb@access.digex.net
http://www.acb.org
1,2,4,5,6,7

American Foundation for the Blind
11 Penn Plaza
New York, NY 10001
(800) 232-5463
(212) 502-7600
(212) 502-7662 (TTY)
afbinfo@afb.org
1,2,4,5,8

Blind Children's Center
4120 Marathon St
Los Angeles, CA 90029
(800) 222-3566
(800) 222-3567 (CA only)
(213) 665-3828 (fax)
info@blindcntr.org
1,2,3,4,8 Spanish materials

Blind Children's Fund Resource Center
2971 53rd St SE
Auburn, WA 98092
(206) 735-6350 (voice/fax)
1,2,4,6

Canadian National Institute for the Blind
1929 Bayview Ave
Toronto, ON CAN M4G 3E8
(416) 486-2500
(416) 480-7417 (TTY)
(416) 480-7699 (fax)
1,2,3,4,6,7,8; French materials

Council of Citizens Low Vision International
6511 26th St W
Bradenton, FL 34207
(800) 733-2258
(941) 755-3846
(941) 755-9721 (fax)
1,2,3,4,5,6,7

Council of Families with Vision Impairment
6212 W Franklin St
Richmond, VA 23226
(804) 288-0395
1,3,4,5,6,7

National Association for Parents of the Visually Impaired
PO Box 317
Watertown, MA 02272-0317
(800) 562-6265
(617) 972-7441
(617) 972-7444 (fax)
1,2,3,4,5,6,7,9

National Association for Visually Handicapped
22 W 21st St, 6th Fl
New York, NY 10010
(212) 889-3141
(212) 727-2931 (fax)
1,2,4,7; Spanish materials, large-print lending library

National Braille Press
88 St Stephen St
Boston, MA 02115
(617) 266-6160
(617) 437-0456 (fax)
dcroft@world.std.com
1,2

National Organization of Parents of Blind Children
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314
(410) 752-5011 (BBS)
(410) 685-5653 (fax)
1,2,3,4,5,6,7

Prevent Blindness America
500 E Remington Rd
Schaumburg, IL 60173-4557
(800) 331-2020
(708) 843-2020
(708) 843-8458 (fax)
1,2,5,6,8; Spanish materials

Recording for the Blind & Dyslexic
20 Roszel Rd
Princeton, NJ 08540
(609) 452-0606
(609) 520-7990 (fax)
2; extensive lending library of academic textbooks on audiocassette (all levels)

The Lighthouse National Center for Vision and Child Development
111 East 59th St
New York, NY 10022
(800) 334-5497
(212) 821-9200
(212) 821-9713 (TTY)
(212) 821-9705 (fax)
mbeck@lighthouse.org
1,2,4,7; Spanish materials

Vision World Wide
5707 Brockton Dr, Ste 302
Indianapolis, IN 46220-5481
(800) 431-1739
(317) 254-1332
(317) 251-6588 (fax)
patprice@aol.com
1,2,4

VITAMIN B12 METABOLISM; INBORN ERROR OF

See: Cobalamin (B12) Defiency

VITILIGO

Canadian Vitiligo Society
Dr. Danuta Pawlowski
Western General Hospital
8th Fl, Rm 542
399 Bathurst St
Toronto, Ontario CAN M5T 2S8
(416) 603-5721

National Vitiligo Foundation
PO Box 6337
Tyler, TX 75711
(903) 534-2925
(903) 534-8075 (fax)
73071.33@compuserve.com
http://pegasus.uthct.edu/Vitiligo/index.html
1,2,5,7,8,9

VOGT CEPHALODACTYLY

See: Apert Syndrome

VON GIERKE DISEASE

See: Glycogen Storage Diseases

VON HIPPEL-LINDAU SYNDROME

See also: Ataxia; Balance Disorders & Dizziness; Brain Tumors; Visual Impairments

Von Hippel-Lindau Syndrome Family Alliance
171 Clinton Rd
Brookline, MA 02146
(800) 767-4845
(617) 232-5946
(617) 734-8233 (fax)
vhl@pipeline.com
1,2,3,4,5,6

VON RECKLINGHAUSEN DISEASE

See: Neurofibromatosis

VON WILLEBRAND DISEASE

See: Hemophilia

VROLIK DISEASE, TYPE II

See: Osteogenesis Imperfecta

WAGNER SYNDROME

See: Stickler Syndrome

WALBAUM-DEHEANE-SCHLEMMER SYNDROME

See: Ectodermal Dysplasias

WALKER-WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WARBURG SYNDROME

See: Hydrocephalus; Lissencephaly

WEAVER SYNDROME

See also: Growth Disorders

Support for Families with Children Having Weaver Syndrome
4357 153rd Ave SE
Bellevue, WA 98006
(206) 747-5382 (US)
(416) 948-5401 (CAN)
3,9

WEAVER-SMITH SYNDROME

See: Weaver Syndrome

WEBER SYNDROME

See: Sturge-Weber Syndrome

WEGENER GRANULOMATOSIS

See also: Immune Disorders

Wegener's Granulomatosis Support Group
PO Box 1518
Platte City, MO 64079-1518
(800) 277-9474
(816) 858-4444 (fax)
1,2,3,4,5,6,7,8

WEISSENBACHER-ZWEYMULLER SYNDROME

See: Stickler Syndrome

WERDNIG-HOFFMAN DISEASE

See: Spinal Muscular Atrophy

WERLHOF DISEASE

See: Purpura, Idiopathic Thrombocytopenia (ITP)

WERMER SYNDROME

See: Multiple Endocrine Neoplasia I

WERNER SYNDROME

See: Progeria

WHISTLING FACE SYNDROME

See: Freeman-Sheldon Syndrome

WHISTLING FACE-WINDMILL VEIN HAND SYNDROME

See: Freeman-Sheldon Syndrome

WHITE MATTER DISORDERS

See: Leukodystrophy

WHITE SPOT DISEASE

See: Vitiligo

WHITNALL-NORMAN SYNDROME

See: Norrie Disease

WILLIAMS SYNDROME

See also: Autism; Attention Deficit Disorder; Growth Disorders; Heart Disorders; Learning Disabilities; Noonan Syndrome

CAWS: Canadian Association for Williams Syndrome
PO Box 2115
Vancouver, BC CAN V6B 3T5
1,2,3,5,9; French materials

Williams Syndrome Association
PO Box 297
Clawson, MI 48017-0297
(810) 541-3630
(810) 541-3631 (fax)
1,2,3,4,5,6,7,8,9; DNA research bank, annual music camp

WILLIAMS-BEUREN SYNDROME

See: Williams Syndrome

WILMS TUMOR

See: Kidney Disorders

WILSON DISEASE

See also: Kidney Disorders; Liver Disorders

Wilson's Disease Association
PO Box 75324
Washington, DC 20013
(800) 399-0266
1,2,3,4,6,7,9

WISKOTT-ALDRICH SYNDROME

See: Immune Disorders; Purpura, Immune Thrombocytopenia

WOLF SYNDROME

See: Wolf-Hirschhorn Syndrome

WOLF-HIRSCHHORN SYNDROME

4p- Parent Network
c/o Becky & Tom Richardson
2048 South 182nd Cir
Omaha, NE 68130
(402) 330-7135
1,2,3,6,9

Wolf-Hirschhorn Syndrome Support Group and Newsletter
5536 Virginia Ct
Amherst, OH 44001
(216) 282-1460
1,2,3,4,6,9

X-LINKED COPPER DEFICIENCY

See: Menkes Disease

X-LINKED COPPER MALABSORPTION

See: Menkes Disease

X-LINKED MYOTUBULAR MYOPATHY

See: Myotubular Myopathy, X-Linked; Muscular Dystrophy

XANTHOGRANULOMATOSIS, JUVENILE

See: Histocytosis

XERODERMA PIGMENTOSUM

Xeroderma Pigmentosum Registry
c/o W. Clark Lambert, MD, PhD
UMD—NJ Medical School
Dept of Pathology, Rm C-520
185 S Orange Ave
Newark, NJ 07103-2714
(201) 982-6255
4,9

XERODERMA-TALIPES-ENAMEL DEFECT

See: Ectodermal Dysplasias

ZANIER-ROUBICEK SYNDROME

See: Ectodermal Dysplasias

ZELLWEGER SYNDROME

See: Leukodystrophy

ZIEHEN-OPPENHEIM DISEASE

See: Dystonia

Matching Resources

This year's directory of "National Resources for Specific Disabilities and Conditions" lists more than 500 organizations. But despite this abundance, some parents may be unable to find the information and support they need. These may include parents who have children with extremely rare conditions or unique combinations of disabilities. Others may be dealing with unique family situations, such as single parenting, raising twins or adoption.

Matching groups—both national and international—can help. These networking organizations do parent-to-parent matching based on children's disabilities and, in some cases, other unique family situations. Most maintain ongoing contact with other groups worldwide.

Each organization's listing is followed by a brief description of the disabilities and conditions with which it deals and the services it provides. Unless otherwise noted, all services are provided free of charge. This symbol (✉) indicates an Internet e-mail address. Where applicable, international dialing codes (for calling from the US or Canada) are placed in parentheses preceding an organization's main telephone number. Please be aware of time zone differences when making any calls, particularly international calls. (Unless otherwise noted, telephone numbers are for voice only.)

Association of Birth Defect Children
827 Irma Ave
Orlando, FL 32803
(800) 313-2232 (24-hour registry line)
(407) 245-7035 (voice/fax)
Offers matching and participation in National Birth Defect Registry. Provides information about birth defects, particularly those thought to be associated with exposure to environmental toxins.

Association of Genetic Support/Australia
66 Albion St
Surry Hills, NSW 2010
Australia
(01161) 2 211 1462
Offers matching for all genetic disorders, particularly rare conditions.

Canadian Organization for Rare Disorders
PO Box 35
Lethbridge, AB T1J 3Y3
Canada
(403) 329-0665
Offers matching services for rare disorders within Canada. Provides printed information on specific rare disorders ($8 each).

The Centre for Rare Diseases and Disabilities
Copenhagen
Bredgade 25
Sct Annae Passage, opg F, 5th Fl
DK-1260 Copenhagen K
Denmark
(01145) 33 91 40 20
(01145) 33 91 40 19 (fax)
Offers matching for rare disorders.

CHASER: Congenital Heart Anomalies Support, Education and Resources
c/o Anita and James Myers
2112 N Wilkins Rd
Swanton, OH 43558
(419) 825-5575
(419) 825-2880 (fax)
Offers matching for all congenital and acquired heart disorders and any disability that includes a heart disorder.

Chromosome Deletion Outreach
PO Box 280
Driggs, ID 83422
(208) 354-8550
(208) 456-2768 (fax)
Offers matching for rare chromosomal disorders including deletions, additions, inversions and translocations.

Contact A Family
c/o Carol Youngs
170 Tottenham Court Rd
London W1P 0HA
England
(01144) 171 383 3555
(01144) 171 383 0259 (fax)
Offers matching for all disabilities, including rare conditions.

COX Foundation for All Mitochondrial Diseases
PO Box 1151
Monroeville, PA 15146-1151
(412) 856-1297 (voice/fax)
✉ 74743.2705@compuserve.com
Offers information and matching for all genetic conditions thought to have a mitochondrial mode of transmission.

MAGIC Foundation for Children's Growth
1327 N Harlem Ave
Oak Park, IL 60302
(800) 362-4423
(708) 383-0808
(708) 383-0899 (fax)
✉ magic@nettap.com
Offers networking for many conditions that may affect a child's physical growth—genetic syndromes, chromosomal disorders, endocrine disorders, metabolic conditions, and both congenital and acquired kidney and liver disorders. Offers informational brochures on many growth disorders.

Mitochondrial Disorders Foundation of America
5100-1B Clayton Rd, Ste 187
Concord, CA 94521
(510) 798-8798 (voice/fax)
✉ 102125.1233@compuserve.com
Offers information and matching for all genetic conditions thought to have a mitochondrial mode of transmission.

MUMS National Parent to Parent Network
c/o Julie Gordon
150 Custer Ct
Green Bay, WI 54301-1243
(414) 336-5333
(414) 339-0995 (fax)
Offers matching based on disability and/or unique family situations.

National Parent-to-Parent Support and Information System
c/o Kathleen Judd
PO Box 907
Blue Ridge, GA 30513
(800) 651-1151 (V/TTY)
(706) 632-8822 (V/TTY)
(706) 632-8830 (fax)
✉ judd103w@wonder.em.cdc.gov
Offers matching for all rare disorders and special health care needs.

National Tay-Sachs and Allied Diseases Association
2001 Beacon St, Ste 204
Brookline, MA 02146
(617) 277-4463
(617) 277-0134 (fax)
Offers matching for many storage disorders including lipid storage diseases (glycosphingolipidoses, mucopolysaccharidoses, oligosaccharidoses, mucolipidoses), leukodystrophies and certain other metabolic disorders. Provides phone cards that allow free telephone networking among parents. Offers printed information in English and Russian.

National Tay-Sachs and Allied Diseases of Ontario
512 Wicklow Rd
Burlington, ON CAN L7L 2H8
(905) 634-4101
Services are the same as National Tay-Sachs and Allied Diseases Association (above) except offers printed information in English and French.

NORD: National Organization for Rare Disorders
PO Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673
(203) 745-6518
(203) 746-6927 (TTY)
(203) 746-6481 (fax)
Provides printed information on specific rare disorders and makes referrals to support groups or matching groups. Paid members ($25/yr) have access to direct parent networking.

Parent-to-Parent Link Programme
The Easter Seal Society, Ontario
250 Ferrand Dr, Ste 200
Toronto, ON M3C 3P2
Canada
(800) 668-6252 (ON only)
(416) 421-8377
(416) 696-1035 (fax)
✉ info@easterseals.org
Offers matching for all disabilities, especially rare conditions.

Parent to Parent New Zealand
PO Box 234
Waikato Mail Centre
Hamilton
New Zealand
(01164) 7 834 1108 (day; voice/fax)
(01164) 7 827 5488 (evening)
Offers matching for rare disabilities and special health care needs. Networks with US, Australia and England.

Rare Chromosome Disorder Group
160 Locket Rd
Harrow Weald
Middlesex
England HA3 7NZ
(01144) 181 863 3557 (voice; evening)
Offers matching for rare chromosomal disorders.

Research Trust for Metabolic Diseases in Children
Golden Gates Lodge
Weston Rd
Crewe
Cheshire
England CW2 5XN
(01144) 1270 250221
(01144) 1270 250244 (fax)
Offers information and matching for more than 200 metabolic diseases.

OTHER RESOURCES

Alliance of Genetic Support Groups
35 Wisconsin Cir, Ste 440
Chevy Chase, MD 20815-7015
(800) 336-4363
(301) 652-5553
(301) 654-0171 (fax)
✉ alliance@capaccess.org
Provides free kits to help people start support groups. Makes referrals to appropriate resources and genetic services. Does not offer any direct parent-to-parent matching.

Search & Respond
c/o Exceptional Parent
209 Harvard St, Ste 303
Brookline, MA 02146
(617) 730-5800
(617) 730-8742 (fax)
Exceptional Parent prints letters from people looking for others dealing with similar disabilities, health care needs or other situations. All replies are forwarded; some are printed in the magazine.

Where's the beach? **Anna Vier Biercevica,** 5, of South Burli Vermont, makes the most of her therapy sessions by singing silly s playing games and using props—t the sunglasses—to liven things u her swimming tube makes a terri seating aid! Anna, who was born p turely, has significant neurologica developmental delays.

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90 West Main St., Troy, PA 16947

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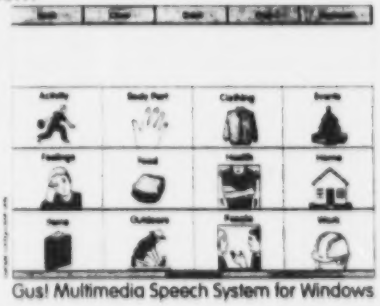

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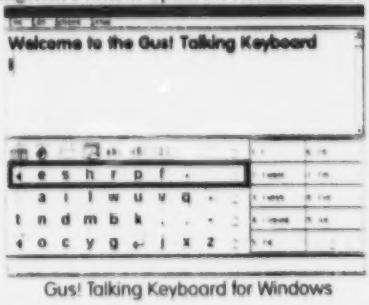

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Gus! Speak Clipboard for Windows
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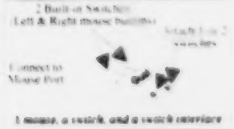

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Circle #103

MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MARKUS SMITH
Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

For more information, contact:

MOVE International,

City Center, 1300 17th St.,

Bakersfield, CA 93301;

(800) 397-6683

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Circle #44 61

Everyday Hero

RICON

A Great Scouting Opportunity.

Troop #767SNS (Special Needs Scouts) of Orange County, CA, is just like any other boy scout troop, except for one thing—every member has a disability. Because most of the boys use wheelchairs, their participation in traditional scouting activities is a major challenge...but one they face with pride and determination. The troop, founded by Bruce Manch, president of Southern California Mobility, is currently raising money to buy a mini-bus equipped with a Ricon lift.

Until then, Bruce's personal van installed with the Ricon S-1231 Clearway Wheelchair Lift is ideal for the troop's transportation needs. Its strong steel frame and powerful hydraulic pump provide a fast, secure means of entry and exit for the scouts. And the fully automatic split platform of the Clearway lift folds up and out of the way, leaving the doorway clear for loading and unloading supplies. We call this the "Ricon Open Door Policy."

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Circle #129

Berkshire Meadows

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Like other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.

The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

Weekends and holidays are for fun. We take full advantage of the loveliness of our natural surroundings, and of the receptive friendliness and extensive activities of local communities.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
249 North Plain Road
Housatonic, MA 01236
(413) 528-2523

Circle #174

Parent Training & Information Centers

Parent Training and Information (PTI) programs are funded by the Division of Personnel Preparation, Office of Special Education Programs in the U.S. Department of Education. Their stated mission is "to provide training and information to parents to enable [them] to participate more effectively with professionals in meeting the educational needs of children with disabilities."

PTIs can help parents to:
- Understand their children's specific needs.
- Communicate more effectively with professionals.
- Participate in the educational planning process.
- Obtain information about relevant programs, services and resources.

For more information, contact the National Parent Network on Disabilities (NPND), 1727 King St., Ste. 305, Alexandria, VA 22314; (703) 684-6763 (V/TTY); (703) 836-1232 (fax).

ALABAMA

Special Education Action Committee
PO Box 161274
Mobile, AL 36616-2274
(800) 222-7322 (voice; AL only)
(334) 478-1208 (V/TTY)
(334) 473-7877 (fax)

ALASKA

PARENT: Parents As Resources Engaged in Networking and Training
540 W International Airport Rd.
Ste 200
Anchorage, AK 99518
(800) 478-7678 (voice; AK only)
(907) 563-2246 (voice)
(907) 563-2257 (fax)
parents@corcom.com

ARIZONA

Pilot Parent Partnerships
4750 N Black Canyon Hwy.
Ste 101
Phoenix, AZ 85017-3621
(800) 237-3007 (voice)
(602) 242-4366 (V/TTY)
(602) 242-4306 (fax)

ARKANSAS

Arkansas Disability Coalition
10002 W Markham, Ste B7
Little Rock, AR 72205
(800) 223-1330 (V/TTY; AR only)
(501) 221-1330 (V/TTY)
(501) 221-9067 (fax)
adc@cei.net

FOCUS
305 W Jefferson Ave
Jonesboro, AR 72401
(501) 935-2750 (voice)
(501) 931-3755 (fax)

CALIFORNIA

DREDF: Disability Rights, Education & Defense Fund
2212 6th St
Berkeley, CA 94710
(800) 466-4232 (voice)
(510) 644-2555 (V/TTY)
(510) 841-8645 (fax)
75452.120@compuserve.com

Exceptional Parents Unlimited
4120 N 1st St
Fresno, CA 93726
(209) 229-2000 (voice)
(209) 229-2956 (fax)

Matrix
555 Northgate Dr. Ste A
San Rafael, CA 94903
(800) 578-2592 (voice; valid only for area codes 415, 707, 916)
(415) 499-3877 (voice)
(415) 507-9457 (fax)
matrix@mann.k12.ca.us

Parents Helping Parents
594 Monterey Blvd
San Francisco, CA 94127
(415) 841-8820 (voice)
(415) 841-8824 (fax)

Parents Helping Parents
3041 Olcott St
Santa Clara, CA 95054
(408) 727-5775 (voice)
(408) 727-0182 (fax)
trudy.grable@php.com

TASK: Team of Advocates for Special Kids
100 W Cerritos Ave
Anaheim, CA 92805
(714) 533-8275 (V/TTY)
(714) 533-2533 (fax)
taskcar@aol.com

COLORADO

PEAK Parent Center
6055 Lehman Dr. Ste 101
Colorado Springs, CO 80918
(800) 284-0251 (voice)
(719) 531-9400 (voice)
(719) 531-9403 (TTY)
(719) 531-9452 (fax)

CONNECTICUT

Connecticut Parent Advocacy Center
PO Box 579, Ste 4
East Lyme, CT 06333
(800) 445-2722 (voice; CT only)
(860) 739-3089 (V/TTY)
(860) 739-7460 (fax)
cpacinc@aol.com

The Family Center
Connecticut Children's Medical Ctr
181 E Cedar St
Newington, CT 06111
(203) 667-5288 (voice)
(203) 665-7976 (fax)

DELAWARE

Parent Information Center of Delaware
700 Barksdale Rd. Ste 3
Newark, DE 19711
(302) 366-0152 (voice)
(302) 366-0178 (TTY)
(302) 366-0276 (fax)

DISTRICT OF COLUMBIA

COPE
300 I St NE, Ste 209
Washington, DC 20002
(800) 515-2673 (voice)
(202) 543-6046 (voice)
(202) 543-6682 (fax)

FLORIDA

Family Network on Disabilities
5510 W Gray St, Ste 220
Tampa, FL 33609-1035
(800) 825-5736 (V/TTY)
(813) 289-1122 (V/TTY)
(813) 286-8614 (fax)

GEORGIA

PEP: Parents Educating Parents
Arc of Georgia
2860 E Point St, Ste 200
East Point, GA 30344
(404) 761-3150 (V/TTY)
(404) 767-2258 (fax)

HAWAII

Learning Disabilities Association of Hawaii
200 N Vineyard Blvd, Ste 310
Honolulu, HI 96817
(800) 533-9684 (V/TTY; HI only)
(808) 536-9684 (V/TTY)
(808) 537-6780 (fax)

IDAHO

Idaho Parents Unlimited
4696 Overland Rd, Ste 478
Boise, ID 83705
(800) 242-4785 (voice; ID only)
(208) 342-5884 (V/TTY)
(208) 342-1408 (fax)

ILLINOIS

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Family Resource Center on Disabilities
20 E Jackson Blvd, Rm 900
Chicago, IL 60604
(800) 952-4199 (voice, IL only)
(312) 939-3513 (voice)
(312) 939-3519 (TTY)
(312) 939-7297 (fax)

National Center for Latinos with Disabilities
1921 S Blue Island
Chicago, IL 60608
(312) 666-3393 (voice)
(312) 666-1788 (TTY)
(312) 666-1787 (fax)

INDIANA

The Indiana Parent Information Network
4755 Kingsway Dr, Ste 105
Indianapolis, IN 46205
(800) 964-4746 (voice)
(317) 257-8683 (voice)
(317) 251-7488 (fax)
ipin@indy.net

IN*SOURCE
809 N Michigan
South Bend, IN 46601
(800) 332-4433 (voice; IN only)
(219) 234-7101 (voice)
(219) 234-7279 (fax)

IOWA

Iowa Pilot Parents
PO Box 1151
Fort Dodge, IA 50501
(800) 952-4777 (voice)
(515) 576-5870 (V/TTY)
(515) 576-8209 (fax)
stuh100w@wonder.em.cdc.gov

KANSAS

Families Together
501 Jackson, Ste 400
Topeka, KS 66603
(800) 264-6343 (V/TTY; KS only)
(913) 233-4777 (V/TTY)
(913) 233-4787 (fax)

KENTUCKY

KY-SPIN: Kentucky Special Parent Involvement Network
2210 Goldsmith Ln. #118
Louisville, KY 40218
(800) 525-7746 (voice)
(502) 456-0923 (V/TTY)
(502) 456-0893 (fax)

LOUISIANA

Project PROMPT
4323 Division St, Ste 110
Metairie, LA 70002-3179
(800) 766-7736 (voice)
(504) 888-9111 (voice)
(504) 888-0246 (fax)

MAINE

Maine Parent Federation
PO Box 2067
Augusta, ME 04338-2067
(800) 870-7746 (V/TTY; ME only)
(207) 582-2504 (V/TTY)
(207) 582-3638 (fax)

MARYLAND

Parents' Place of Maryland
7257 Parkway Dr, Ste 210
Hanover, MD 21076
(410) 712-0900 (V/TTY)
(410) 712-0902 (fax)
parplace@aol.com

Parents' Place of Western Maryland
23 E Frederick St
Walkersville, MD 21793
(800) 394-5694 (voice)
(301) 898-0936 (voice)
(301) 845-2156 (fax)

MASSACHUSETTS

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(800) 331-0688 (voice, MA only)
(617) 482-2915 (V/TTY)
(617) 695-2939 (fax)

MICHIGAN

CAUSE: Citizens' Alliance to Uphold Special Education
3303 W Saginaw, Ste F1
Lansing, MI 48917
(800) 221-9105 (V/TTY; MI only)
(517) 886-9167 (V/TTY)
(517) 886-9775 (fax)

Parents Are Experts
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Southfield, MI 48075-3744
(810) 557-5070 (V/TTY)
(810) 557-4456 (fax)

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PACER Center
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Minneapolis, MN 55417-1098
(800) 537-2237 (voice; MN only)
(612) 827-2966 (V/TTY)
(612) 827-3065 (fax)
mnpacer@gteens.com

MISSISSIPPI

Parent Partners
3111 N State St
Jackson, MS 39216
(800) 366-5707 (voice; MS only)
(601) 366-5707 (voice)
(601) 362-7361 (fax)

Project Empower
PO Box 851
Greenville, MS 38702-8051
(800) 337-4852 (voice)
(601) 332-4852 (voice)
(601) 332-1622 (fax)

MISSOURI

MPACT: Missouri Parents Act
2100 S Brentwood, Ste G
Springfield, MO 65804
(800) 743-7634 (voice; MO only)
(417) 882-7434 (V/TTY)
(417) 882-8413 (fax)

MPACT: Missouri Parents Act, Kansas City
3100 Main, Ste 303
Kansas City, MO 64111
(816) 531-7070 (voice)
(816) 531-4777 (fax)

MPACT: Missouri Parents Act, St Louis
8631 Delmar, Ste 300
St Louis, MO 63124
(800) 995-3160 (voice; MO only)
(314) 997-7622 (V/TTY)
(314) 997-5518 (fax)

BEST COPY AVAILABLE

PARENT TRAINING & INFORMATION CENTERS

MONTANA

PLUK: Parents, Let's Unite for Kids
MSU Billings, SPED 267
1500 N 30th
Billings, MT 59101-0298
(800) 222-7585 (voice)
(406) 657-2055 (voice)
(406) 657-2061 (fax)
pluk@msubillings.com

NEBRASKA

Nebraska Parent Information & Training Center
3610 Dodge St, Ste 102
Omaha, NE 68131
(800) 284-8520 (voice)
(402) 346-0525 (V/TTY)
(402) 346-5253 (fax)

NEVADA

Nevada PEP: Parents Encouraging Parents
4970 Arville St, Ste 110
Las Vegas, NV 89118
(800) 216-5165 (voice; NV only)
(702) 248-6711 (voice)
(702) 367-9812 (fax)

Northern PEP: Parents Encouraging Parents
1359 Kim Pl
Minden, NV 89423
(800) 216-5188 (voice)
(702) 267-3237 (voice/fax)

NEW HAMPSHIRE

Parent Information Center
PO Box 1422
Concord, NH 03302-1422
(800) 232-0986 (voice; NH only)
(603) 224-7005 (V/TTY)
(603) 224-4365 (fax)

NEW JERSEY

SPAN: Statewide Parent Advocacy Network
516 North Ave E
Westfield, NJ 07090-1446
(800) 654-7726 (voice; NJ only)
(908) 654-7726 (V/TTY)
(908) 654-7880 (fax)

NEW MEXICO

EPICS
PO Box 788
Bernalillo, NM 87004
(800) 765-7320 (voice)
(505) 867-3396 (voice)
(505) 867-3398 (fax)
s1c2r3@indirect.com

Parents Reaching Out to Help
1000A Main St NE
Los Lunas, NM 87031
(800) 524-5176 (V/TTY)
(505) 865-3700 (V/TTY)
(505) 865-3717 (fax)

NEW YORK

Advocates for Children of New York
105 Court St
Brooklyn, NY 11201
(718) 729-8866 (voice)
(718) 729-8931 (fax)

Parent Network Center of New York
250 Delaware Ave
Buffalo, NY 14202
(800) 724-7408 (voice; NY only)
(716) 885-1004 (voice)
(716) 885-3527 (TTY)
(716) 885-9547 (fax)

Resources for Children with Special Needs
200 Park Ave S, #816
New York, NY 10003
(212) 677-4650 (voice)
(212) 254-4070 (fax)

Sinergia
15 W 65th St, 6th Fl
New York, NY 10023
(212) 496-1300 (voice)
(212) 496-5608 (fax)

NORTH CAROLINA

Exceptional Children's Assistance Center
PO Box 16
Davidson, NC 28036
(800) 962-6817 (voice; NC only)
(704) 892-1321 (voice)
(704) 892-5028 (fax)

NORTH DAKOTA

Native American Experimental Parent Training & Information Center
Arrowhead Shopping Ctr
16th St & 2nd Ave SW
Minot, ND 58701
(800) 245-5840 (voice; ND only)
(701) 852-9426 (voice)
(701) 852-9436 (TTY)
(701) 838-9324 (fax)
kjel100w@wonder.em.cdc.gov

Pathfinder Parent Training & Information Center
Arrowhead Shopping Ctr
16th & 2nd Ave SW
Minot, ND 58701
(800) 245-5840 (voice; ND only)
(701) 852-9426 (voice)
(701) 852-9436 (TTY)
(701) 838-9324 (fax)
kjel100w@wonder.em.cdc.gov

OHIO

Child Advocacy Center
1821 Summit Rd, Ste 303
Cincinnati, OH 45237
(513) 821-2400 (V/TTY)
(513) 821-2442 (fax)

Ohio Coalition for the Education of Children with Disabilities
165 W Center St, Ste 302
Marion, OH 43302
(800) 374-2806 (V/TTY)
(614) 382-5452 (V/TTY)
(614) 383-6421 (fax)

OKLAHOMA

Pro-Oklahoma/Parent Training and Information Project
1917 S Harvard Ave
Oklahoma City, OK 73128
(800) 759-4142 (V/TTY)
(405) 681-9710 (V/TTY)
(405) 685-4006 (fax)
prook1@aol.com

OREGON

Oregon COPE Project
999 Locust St
Salem, OR 97303
(503) 373-7477 (V/TTY/fax)

PENNSYLVANIA

Arc of Lehigh & Northhampton
1036 N Godfrey St
Allentown, PA 18103
(610) 434-8076 (voice)
(610) 434-6202 (fax)

Mentor Parent Program
PO Box 718
Seneca, PA 16346
(800) 447-1431 (voice; PA only)
(814) 676-8615 (voice)
(814) 677-4465 (fax)

Parent Education Network
333 E 7th Ave
York, PA 17404
(800) 522-5827 (V/TTY; PA only)
(717) 845-9722 (voice)
(717) 848-3654 (fax)

Parents Union for Public Schools
311 S Juniper St, Ste 602
Philadelphia, PA 19107
(215) 546-1166 (voice)
(215) 731-1688 (fax)

PUERTO RICO

Associacion de Padres por Bienestar de Ninos Impedidos de Puerto Rico
PO Box 21301
Rio Piedras, PR 00928-1301
(809) 763-4665 (voice)
(809) 765-0345 (fax)

RHODE ISLAND

Rhode Island Parent Information Network
500 Prospect St, Wing D
Pawtucket, RI 02860
(800) 464-3399 (voice; RI only)
(401) 727-4144 (voice)
(401) 727-4151 (TTY)
(401) 725-9960 (fax)

SOUTH CAROLINA

Parents Reaching Out to Parents of SC
2712 Middleburg Dr, Ste 102
Columbia, SC 29204
(800) 759-4776 (V/TTY; SC only)
(803) 779-3859 (V/TTY)
(803) 252-4513 (fax)

SOUTH DAKOTA

South Dakota Parent Connection
3701 W 49th St, Ste 200B
Sioux Falls, SD 57106
(800) 640-4553 (V/TTY; SD only)
(605) 361-3171 (voice)
(605) 361-2928 (fax)
dbehl@sdparentconnection.com

TENNESSEE

Project STEP: Support & Training for Exceptional Parents
1104 Tusculum Blvd, Ste 401
Greeneville, TN 37745
(800) 280-7837 (voice; TN only)
(800) 639-2464 (TTY; TN only)
(423) 639-0125 (voice)
(423) 636-8217 (fax)
tnstep@aol.com

TEXAS

Partners Resource Network
1090 Longfellow Dr, Ste B
Beaumont, TX 77706-4889
(800) 866-4726 (voice; TX only)
(409) 898-4684 (V/TTY)
(409) 898-4869 (fax)

Project PODER
2300 W Commerce, Ste 205
San Antonio, TX 78207
(800) 682-9747 (V/TTY; TX only)
(210) 222-2637 (V/TTY)
(210) 222-2638 (fax)

Special Kids
PO Box 61628
Houston, TX 77208-1628
(713) 643-9576 (V/TTY)
(713) 643-6291 (fax)
speckids@aol.com

UTAH

Utah Parent Center
2290 E 4500 S, #110
Salt Lake City, UT 84117
(800) 468-1160 (V/TTY; UT only)
(801) 272-1051 (V/TTY)
(801) 272-8907 (fax)

VERMONT

Vermont Parent Information Center
Chace Mill, 1 Mill St, Ste A7
Burlington, VT 05401
(800) 639-7170 (V/TTY; VT only)
(802) 658-5315 (voice)
(802) 658-5395 (fax)

VIRGIN ISLANDS

VI FIND: Family Information Network on Disabilities
#6 7th St, Sugar Estate
PO Box 11670
St Thomas, USVI 00801
(809) 774-1662 (voice)
(809) 774-1642 (TTY)
(809) 774-7844 (fax)

VI FIND, St Croix
7A Whim
Frederiksted
St Croix, USVI 00840
(809) 772-9135 (voice)
(809) 772-4641 (TTY)
(809) 772-0609 (fax)

VI FIND, St John
Morris de Castro Clinic
Cruz Bay
St John, USVI 00830
(809) 779-4333 (voice/fax)

VIRGINIA

PEATC: Parent Educational Advocacy Training Center
10340 Democracy Ln, Ste 206
Fairfax, VA 22030
(800) 869-6782 (V/TTY; VA only)
(703) 691-7826 (V/TTY)
(703) 691-8148 (fax)
peatcinc@aol.com

WASHINGTON

STOMP: Specialized Training of Military Parents
12208 Pacific Hwy SW
Tacoma, WA 98499
(800) 298-3543 (voice)
(206) 588-1741 (V/TTY)
(206) 984-7520 (fax)
pavestomp@aol.com

Touchstones
6721 51st Ave S
Seattle, WA 98118
(206) 721-0867 (V/TTY)
(206) 721-2422 (fax)

Washington PAVE
6316 S 12th
Tacoma, WA 98465
(800) 572-7368 (V/TTY; WA only)
(206) 565-2266 (V/TTY)
(206) 566-8052 (fax)
wapave@nwrain.com

WEST VIRGINIA

West Virginia Parent Training & Information Center
Colonial Village, 104 E Main St, #3B
Clarksburg, WV 26301
(800) 281-1436 (V/TTY; WV only)
(304) 624-1436 (V/TTY)
(304) 624-1438 (fax)

WISCONSIN

Parent Education Project of Wisconsin
2192 S 60th St
West Allis, WI 53219
(800) 231-8382 (voice; WI only)
(414) 328-5520 (voice)
(414) 328-5527 (TTY)
(414) 328-5530 (fax)

WYOMING

Wyoming Parent Information Center
5 N Lobban
Buffalo, WY 82834
(800) 660-9742 (V/TTY; WY only)
(307) 684-2277 (V/TTY)
(307) 684-5314 (fax)

Who's that four-year-old trendsetter? Jack Williams, III loves to sport his Barney fashion-wear. According to his mother, Cathy, "Jack is one of Barney's biggest fans." Jack, who lives in Findlay, Ohio, has congenital hypomyelination neuropathy and is looking forward to receiving a power wheelchair. He enjoys preschool, playing with toy cars and spending time with his sister, Tiffany, 14.

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Beverly Hills, CA 90210

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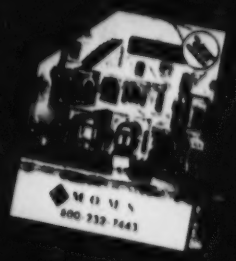

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Bed-wetting is a common problem for older children. Five to fifteen percent of all older children experience night-time accidents.

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Address: _____

City, State, ZIP: _____

Phone: ( ) _____

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Circle #204

Parent to Parent Programs

Parent to Parent (P-P) programs offer a special kind of support to parents and caregivers of children with special needs. Hundreds of active P-P programs in the United States provide emotional and informational support to parents by matching a parent who is referred to the program with a trained, experienced "veteran" parent who has already "been there" and can lend helpful support. Because the two parents share so many common experiences, they often form an immediate bond. Such one-to-one relationships provide more intimate and individualized support than can be found in most traditional parent support groups.

Parent to Parent programs have been providing these one-to-one matches for 25 years. The major components of P-P programs continue to include screening and training of veteran parents, careful matches—based on family and disability issues—between veteran and referred parents, and follow-up support. Many local P-P programs also offer a range of other activities including parent support groups for education and support, social events, resource libraries and services for other family members as well.

Some states also have a statewide P-P program that offers training and technical assistance to local programs. These statewide P-P programs often have extensive computerized databases that allow them to make a statewide match when an appropriate local match cannot be found.

1996 CONFERENCE

Every other year, parents and families connect with each other at an international P-P conference. The Eighth International P-P Conference will be held March 29–April 1, 1996 in Albuquerque, New Mexico. Conference planners are expecting 2000 participants. To obtain conference registration materials, write to Parents Reaching Out, PO Box 2640, Los Lunas, NM 87031, or call (800) 564-4772.

USING THIS DIRECTORY

The Beach Center on Families and Disability at the University of Kansas compiled this listing of P-P programs by requesting updated information from each program that appeared in the 1995 directory. New programs are also included.

Programs within this directory are categorized by state and alphabetized by town or city within each state listing. Statewide P-P programs are identified by an astersk (*) following the program name. A few states have chosen to list only their statewide P-P program, which can make referrals to local programs. In other states, statewide programs can provide contact information about additional local programs not appearing in the directory.

Corrections or additions to the directory should be sent to the Beach Center on Families and Disability, 3111 Haworth Hall, University of Kansas, Lawrence, KS 66045; (913) 864-7600 (V/TTY), (913) 864-7605 (fax).

ALABAMA

Friends for Life
c/o Auburn United Methodist Church
220 E Magnolia
Auburn, AL 36830
(334) 826-8800

Project AIM
Dept of Rehabilitation and Special Education
1229 Haley Ctr
Auburn University
Auburn, AL 36830
(334) 884-2101

Special Education Action Committee
Birmingham Outreach Office
25 W Oxmoor Rd, Ste 50
Birmingham, AL 35209
(205) 941-0313 (V/TTY)
(205) 941-0987 (fax)

The Arc of Morgan Cty
2046 Beltline Hwy, Ste 4
Decatur, AL 35601
(205) 355-6192

Special Education Action Committee
3207 International Dr W, Ste C
Mobile, AL 36606
(800) 222-7322 (AL only)
(334) 478-1208 (V/TTY)
(334) 473-7877 (fax)

Special Education Action Committee
Huntsville Outreach Office
3322 S Memorial Pkwy, Ste 15
Huntsville, AL 35801
(205) 882-3911
(205) 882-3974 (fax)

ARKANSAS

Arc of Arkansas—Parent to Parent*
2000 Main St
Little Rock, AR 72206
(501) 375-7770
(501) 372-4621 (fax)

ARIZONA

Reaching Harmony
PO Box 920
Fort Defiance, AZ 86504
(800) 554-9881 (AZ only)
(520) 729-5888

Pilot Parent Partnerships*
4750 N Black Canyon, Ste 101
Phoenix, AZ 85017
(602) 242-4366 (V/TTY)
(602) 242-4306 (fax)

Pilot Parents of Southern Arizona
2600 N Wyatt Dr
Tucson, AZ 85712
(520) 324-3150

CALIFORNIA

HEARTS Connection Family Resource Center
3200 N Sillect Ave
Bakersfield, CA 93308
(805) 327-8531, ext 282
(805) 327-1251 (TTY)
(805) 324-5060 (fax)

Family Resource Network
PO Box 3697
Chico, CA 95927
(916) 894-5879

Special Care Parents
PO Box 111
Citrus Heights, CA 95611-0111
(916) 658-8588

Humble Child Care Counsel
805 7th St
Eureka, CA 95502
(707) 444-8293
(707) 444-8298 (fax)

Exceptional Parents Unlimited
4120 N First St
Fresno, CA 93726
(209) 229-2000
(209) 229-2956 (fax)

Comfort Connection
12361 Lewis St, Ste 101
Garden Grove, CA 92640
(714) 748-7491
(714) 748-8149 (fax)

Frank D Lanterman Regional Center
Koch-Young Family Resource Ctr
3440 Wilshire Blvd, Ste 400
Los Angeles, CA 90010
(213) 383-1300
(213) 427-2381 (fax)

Cleft Parent Guild
7120 Franklin Ave
Los Angeles, CA
(213) 874-3300

California Association for Parents of the Visually Impaired
PO Box 1126
Los Gatos, CA 95032
(909) 945-5619 (Southern CA)
(909) 927-8926 (Northern CA)

CHALLENGED Parent-Directed Family Resource Center
621 W Main St
Merced, CA 95340
(209) 385-8454
(209) 385-8483 (fax)

Family Resource Center
18111 Nordhoff St
Northridge, CA 91330-8265
(818) 717-5575
(818) 717-5574 (fax)

DES Action
1615 Broadway, Ste 510
Oakland, CA 94612
(800) 337-9288
(510) 465-4815 (fax)
desact@well.com

Parent to Parent Infant Support Group
Children's Hospital of Orange Cty
455 S Main St
Orange, CA 92668
(714) 532-8521

PROUD
PO Box 5822
Orange, CA 92667-5822
(714) 974-6417
proudoccal@aol.com

Touchstone Support Network
378 Cambridge Ave, Ste K
Palo Alto, CA 94306
(415) 328-4495
tchsupnet@aol.com

Warmline Family Resource Center
9175 Kiefer Blvd, Ste 136
Sacramento, CA 95826
(800) 660-7995 (Six-Cty area)
(916) 631-7995
(916) 942-2157 (fax)

Exceptional Family Resource Center
9245 Sky Pk Ct, Ste 130
San Diego, CA 92123
(619) 268-8252
(619) 268-4275 (fax)

MATRIX Parent Network and Resource Center
555 Northgate Dr, Ste A
San Rafael, CA 94903
(415) 499-3877
(415) 507-9457 (fax)
matrix@marin.k12.ca.us

Family Support Network
1850 E 17th St, Ste 109
Santa Ana, CA 92705
(714) 543-7600
(714) 543-2766 (fax)

United Cerebral Palsy Association of Orange Cty
Family Support Services
3010 W Harvard St, #0
Santa Ana, CA 92704
(714) 557-1291
(714) 546-0943 (fax)
ucpaoc@aol.com

Parents Helping Parents
3041 Olcott St
Santa Clara, CA 95054-3222
(408) 727-5775
(408) 727-0182 (fax)

One in a Million Kids
PO Box 156
Seal Beach, CA 90740
(310) 588-2562
(310) 493-3634 (fax)

Direct Link for the Disabled
PO Box 1036
Solvang, CA 93464
(805) 688-1603
(805) 686-5285 (fax)

COLORADO

Communication Disorders Clinic University of Colorado at Boulder
Campus Box 409
Boulder, CO 80309-0409
(303) 492-5375
(303) 492-1355 (TTY)
(303) 492-3274 (fax)
dowell@spot.colorado.edu

Little People of America
7117 E Enclid Dr
Englewood, CO 80111
(303) 740-8555

Effective Parents Project
255 Main St
Grand Junction, CO 81501
(970) 241-4068
(970) 241-3725 (fax)

Mile High Down Syndrome Association
PO Box 620847
Littleton, CO 80162
(303) 797-1699
(303) 347-2938 (fax)

Boulder County Spokespeople
312 Pikes Peak Pl
Longmont, CO 80501
(303) 776-3413

CONNECTICUT

Parents Available to Help
42 Brookwood Dr
Branford, CT 06405
(800) 399-7284 (CT only)
(203) 488-9640 (voice/fax)

Cornelia De Lange Syndrome Foundation
60 Dyer Ave
Collinsville, CT 06022-1273
(800) 223-8355
(860) 693-0159
(860) 693-6819 (fax)

WeCAHR Parent to Parent
11 Lake Ave Ext
Danbury, CT 06811
(203) 792-3540
(203) 794-1620 (fax)

Parent to Parent of Lower Fairfield Cty
50 Glenville St
Greenwich, CT 06831
(203) 531-1880, ext 132
(203) 531-9367 (fax)

Parent to Parent of Connecticut*
Connecticut Children's Medical Ctr
181 E Cedar St
Newington, CT 06111
(860) 667-5288
(860) 665-7976 (fax)

Oxford Specialist Education Parent Support Group
10 Whitegate Rd
Oxford, CT 06478-1501
(203) 888-7326

Center for Independent Living of SW Connecticut
30 Ferry Blvd
Stratford, CT 06497
(203) 378-6977
(203) 378-3248 (TTY)
(203) 375-2748 (fax)

Parent to Parent of Lower Fairfield County
142 Old Ridgefield Rd
Wilton, CT 06897
(203) 762-0089
(203) 761-0811 (fax)

DISTRICT OF COLUMBIA

COPE: Creating Opportunities for Parent Empowerment
800 I St NE, Ste 209
Washington, DC 20002
(800) 515-2673
(202) 543-6482
(202) 543-6682 (fax)

FLORIDA

Gold Coast Down Syndrome Organization
22626 SW 65 Terr
Boca Raton, FL 33428
(407) 451-2163

Parent to Parent of Palm Beach Cty
500 NE Spanish River Blvd, Ste 10A
Boca Raton, FL 33431
(407) 368-1608 (voice/fax)

Parent to Parent of Pinellas Cty
JULE Family Services
1960 E Druid Rd
Clearwater, FL 34624
(813) 462-9606
(813) 462-9680 (fax)

Parent to Parent of W Volusia Cty
2633 Treehaven Dr
Deltona, FL 32738
(904) 789-2330
(904) 532-0731 (voice/fax)

Family Network on Disabilities of Broward Cty
100 S Andrews Ave
Ft Lauderdale, FL 33315
(954) 765-6722
(954) 765-6962 (fax)
fndbrow@bcfreenet.seflin.lib.fl.us

Parent to Parent of St Lucie Cty
5006 Citrus Ave
Ft Pierce, FL 34982
(407) 465-1786
(407) 489-3603 (fax)

Parent to Parent of Miami
5555 SW 93rd Ave
Miami, FL 33165
(305) 271-9797
(305) 598-7752 (fax)

Parent to Parent, Hispanic
5555 SW 93rd Ave
Miami, FL 33165
(305) 271-9797
(305) 598-7752 (fax)

Veteran Intensive Care Parents
PO Box 2700, Ste 1N
Pensacola, FL 32513-2700
(904) 474-7656
(904) 474-7348 (fax)

Parent to Parent of S Brevard
Children's Medical Services
1133 Seminole Dr
Rockledge, FL 32955
(407) 690-3850
(407) 722-8668
(407) 728-5275 (fax)

Special Beginnings c/o NICU
Sarasota Memorial Hospital
1700 S Tamiami Tr
Sarasota, FL 34239-3555
(941) 917-2470

Face of Sarasota
PO Box 1424
Sarasota, FL 34230
(941) 349-5484 (voice/fax)

Family Network on Disabilities*
5510 Gray St, Ste 220
Tampa, FL 33624
(800) 825-5736 (FL only)
(813) 289-1122 (V/TTY)
(813) 286-8614 (fax)

Parent to Parent of Indian River Cty
PO Box 6963
Vero Beach, FL 32961
(407) 770-0683

GEORGIA

Parent to Parent of Georgia*
2900 Woodcock Blvd, Ste 240
Atlanta, GA 30341
(770) 451-5484
(770) 458-4091 (fax)
72137.574@compuserve.com

National Parent to Parent Support and Information System
PO Box 907
Blue Ridge, GA 30513
(800) 651-1151 (V/TTY)
(706) 632-8822 (V/TTY)
(706) 632-8830 (fax)
judd103w@wonder.em.cdc.gov

HAWAII

Hawaii Down Syndrome Congress
419 Keoniana St, #804
Honolulu, HI 96815
(808) 949-1999
(808) 536-3765 (fax)
comray@aol.com

IDAHO

Parents Reaching Out to Parents
2195 Ironwood Ct
Coeurd'Alene, ID 83814
(208) 769-1409
(208) 769-1430 (fax)

Idaho Autism Association
545 N 100 W
Jerome, ID 83338
(208) 324-2927

Parent to Parent
2714 8th Ave
Lewiston, ID 83501
(208) 746-8599

Idaho Autism Association
2470 Warren Ave
Twin Falls, ID 83301
(208) 324-2027

ILLINOIS

Archway
1108 W Willow
Carbondale, IL 62903
(618) 549-4442
(618) 549-0231 (fax)

Developmental Services Center
1304 W Bradley
Champaign, IL 61821
(217) 359-0287
(217) 356-9851 (fax)

Parent to Parent Network
825 18th St
Charleston, IL 61920
(217) 348-0127
(217) 348-0740 (fax)

Illinois Next Steps
Dept of Rehabilitation Services
100 W Randolph, Ste 8-100
Chicago, IL 60601
(800) 275-3677 (IL only)
(312) 814-4042 (V/TTY)

Keshet—Jewish Parents of Children with Special Needs
3210 Dundee Rd
Northbrook, IL 60062
(708) 205-0274
(708) 205-1530 (fax)
keshet1@aol.com

National Association for Down Syndrome
PO Box 4542
Oak Brook, IL 60522-4542
(708) 325-9112
(708) 325-8842 (fax)

Parent to Parent–S Cook Greater Interagency Council
Governor's State University
University Park, IL 60466-0975
(708) 534-4369
(708) 534-8451 (fax)

INDIANA

New Horizons
PO Box 98
Batesville, IN 47006-0098
(812) 934-4528
(812) 934-2522 (fax)

Connection for Special Kids
692 E State Rd 218
Berne, IN 46711
(219) 589-3543

Down Syndrome Support Association of Central Indiana
10792 Downing St
Carmel, IN 46033-3869
(317) 574-9757

Neo Fight
4363 Idlewild Ln
Carmel, IN 46033
(317) 843-0850

PATH
Old Ct House Ctr, Ste 101
201 NW 4th St
Evansville, IN 47708
(812) 424-8600
(812) 424-8603 (fax)

Cleft Lip and Palate Support Network
1609 California Ave
Ft Wayne, IN 46805
(219) 426-1258 (voice/fax)

The Indiana Parent Information Network*
4755 Kingsway Dr, Ste 105
Indianapolis, IN 46205
(317) 257-8683
(317) 251-7488 (fax)

Project Special Care
4755 Kingsway Dr, Ste 105
Indianapolis, IN 46205
(317) 257-8683
(317) 251-7488 (fax)

Special Education Parents Advisory Council
202 W 47th St
Indianapolis, IN 46208-3510
(317) 259-1827
(317) 259-1790 (fax)

Parent Care
9041 Colgate St
Indianapolis, IN 46268-1210
(317) 872-9913
(317) 872-0795 (fax)

QUEST
2711 W Mapel St
Kokomo, IN 46901
(317) 457-3850
(317) 457-9080 (fax)

Wabash Center First Steps
PO Box 6449
2000 Greenbush St
Lafayette, IN 47903-6449
(317) 423-5531 (V/TTY)
(317) 423-4235 (fax)

Everybody Counts Center for Independent Living
6701 Broadway
Merrillville, IN 46410
(219) 769-5055
(219) 769-5325 (fax)

First Steps Early Intervention
Family Support and Preservation
1642 W McLain
Scottsburg, IN 47170
(812) 752-4892
(812) 752-4961 (fax)

Parent, Family, Alumni Support Group
Memorial Hospital NICU
615 N Michigan St
S Bend, IN 46601
(219) 284-7548
(219) 284-3672 (fax)

First Steps for Families
500 8th Ave
Terre Haute, IN 47804
(800) 742-0787, ext 337 (IN only)
(812) 231-8337
(812) 232-8228 (fax)
famnetwork@aol.com

Knox Cty Advocates
1806 Indiana Ave
Vincennes, IN 47591
(812) 882-0375
(812) 886-1128 (fax)

Assistive Technology, Training and Information Center
PO Box 2441
3354 Pine Hill Dr
Vincennes, IN 47591
(800) 962-8842 (V/TTY)
(812) 886-0575 (V/TTY)
(812) 886-1128 (fax)

Family Resource Center of SE Indiana
4101 Timberview Rd
W Harrison, IN 47060
(812) 637-1445

First Directions
PO Box 2482
W Lafayette, IN 47906
(317) 423-1460

IOWA

Autism Society of the Quad Cities
PO Box 472
Bettendorf, IA 52722
(319) 386-6359
gkarp@saunix.sau.edu

Family Educator Connection Program
3706 Cedar Heights Dr
Cedar Falls, IA 50613
(319) 273-8265
(319) 273-8291 (TTY)
(319) 273-8275 (fax)

The Arc of E Central Iowa
Pilot Parents
136 36th St SE, Ste A-5
Cedar Rapids, IA 52403-1128
(800) 843-0272 (IA only)
(319) 365-0487
(319) 365-9938 (fax)

Autism Society of the Quad Cities
4721 Belle Ave
Davenport, IA 52807
(319) 386-6359
(319) 359-5414 (voice/fax)
gkarp@saunix.sau.ed

Parent-Educator Connection Program
MPRRC/Drake University
2507 University Ave
Des Moines, IA 50311
(515) 271-3936
(515) 271-4185 (fax)
ds2741s@acad.drake.edu

Epilepsy Support Group
666 Walnut St, Ste 2500
Des Moines, IA 50309-3993
(515) 288-2500
(515) 243-0654 (fax)

Special Care Parents, Polk Cty
637 7th St
Des Moines, IA 50265
(515) 255-5943

Iowa Pilot Parents*
13 N 12th St, PO Box 1151
Fort Dodge, IA 50501
(515) 576-5870 (V/TTY)
(515) 576-8209 (fax)

Tourette Syndrome
2500 S Center, Ste 233
Box 416
Marshalltown, IA 50158
(515) 753-4157
(515) 752-0510 (fax)

Parent Educator Connection
1382 4th Ave NE
Sioux Center, IA 51250
(800) 572-5073
(712) 772-4374
(712) 722-1643 (fax)

KANSAS

Parent to Parent of Dodge City
PO Box 547
Bucklin, KS 67834
(316) 826-3874

Parent to Parent of Southern Johnson Cty
200 E 5th, Box 163
Edgerton, KS 66021
(913) 780-4700

Special Families
5952 NW 20th
El Dorado, KS 67042
(316) 752-3208

BEST COPY AVAILABLE

PARENT TO PARENT PROGRAMS

Parent to Parent of Garden City
116 E Chestnut, Ste 103
Garden City, KS 67838
(316) 276-6364

Parent to Parent of NW Kansas
Box 15
Gem, KS 67734
(913) 462-6857

Parent to Parent of Ellis Cty
1706 Agnes Dr
Hays, KS 67601
(913) 625-4010

Parent to Parent of Wyandotte Cty
2234 Garfield Ave
Kansas City, KS 66104
(913) 342-9833

Parent to Parent of Douglas Cty
Rte 3, Box 56
Lawrence, KS 66044
(913) 832-1430

Parents Who Care
413 Sherry Pl
Manhattan, KS 66502
(913) 539-8427

Parent to Parent of S Central Kansas
500 S Main
Medicine Lodge, KS 67104
(316) 886-3590

Parent to Parent of Jefferson and Atchison Ctys
Rt 1, Box 80
Oskaloosa, KS 66066
(913) 863-3257

Parent to Parent of Johnson Cty
12680 W 105th St
Overland Pk, KS 66215
(913) 492-5848

SE Kansas Parent to Parent
3118 Corning
Parsons, KS 67357
(800) 362-0390, ext 1859 (KS only)
(316) 421-6550, ext 1859

Families Together*
501 Jackson St, Ste 400
Topeka, KS 66603
(800) 264-6343 (KS only)
(913) 233-4777
(913) 233-4787 (fax)

Parent to Parent
2218 Wilmington Ct
Topeka, KS 66606
(913) 235-9680

Parent to Parent, Sedgwick Cty
3330 W Douglas, Ste 102
Wichita, KS 67203
(316) 945-7747

KENTUCKY

Parent Information Network of Kentucky*
PO Box 5266
Louisville, KY 40255-0266
(502) 485-0035

Parents Outreach
1146 S Third St
Louisville, KY 40203
(502) 584-1239
(502) 584-1261 (fax)

Parents Confronting Dual Sensory Impairment
3816 Brentwood Dr, Ste 2
Owensboro, KY 42301
(502) 683-8283 (voice/fax)

LOUISIANA

Parent Conference on Special Education
State Dept of Special Ed
Office of Special Ed Services
PO Box 94064
Baton Rouge, LA 70804
(504) 763-3588
(504) 763-3553 (fax)

Louisiana Rett Syndrome Foundation
7629 Sailfish Dr
Lake Charles, LA 70605
(318) 474-5727

Parent to Parent of Louisiana Family Support Program
Children's Hospital
200 Henry Clay Ave
New Orleans, LA 70118
(504) 896-9268
(504) 896-3992 (fax)
76020.3545@compuserve.com

Concerned Parents for Students' Educational Rights
1022 Gulf Ln
Sulphur, LA 70663
(318) 528-2191
(318) 625-7591 (fax)

MAINE

Parent Program Mid-Coast Children's Services
11 Maple St
Rockland, ME 04841
(207) 594-8484
(207) 594-5227 (fax)

York Cty Parent Awareness
150 Main St, Midtown Mall
Sanford, ME 04073
(207) 324-2337

MARYLAND

Maryland Infants & Toddlers Program/Family Support Network
Governor's Office for Children, Youth & Families
301 W Preston St
Baltimore, MD 21201
(410) 225-4160
(410) 333-7492 (fax)

National Organization of Parents of Blind Children
1800 Johnson St
Baltimore, MD 21230
(410) 659-9314
(410) 685-5653 (fax)

Partners in Intensive Care
PO Box 41043
Bethesda, MD 20824-1043
(301) 681-2708
(301) 681-2707 (fax)

Learning Disabilities Association of Metropolitan Baltimore
76 Cranbrook Rd, Ste 299
Cockeysville, MD 21030
(410) 821-7010

Epilepsy Foundation of America
4351 Garden City Dr
Landover, MD 20785
(800) 332-1000
(800) 332-2070 (TTY)
(301) 577-4941 (fax)
postmaster@efa.org

Parent to Parent
The Arc of Montgomery Cty
11600 Nebel St
Rockville, MD 20852
(301) 984-5792
(301) 816-2429 (fax)

MASSACHUSETTS

Family Ties
Massachusetts Dept of Public Health
DCSHCN 4th Fl
205 Washington St
Boston, MA 02108
(617) 624-5070

Federation for Children with Special Needs
95 Berkeley St, Ste 104
Boston, MA 02116
(617) 482-2915
(617) 695-2939 (fax)

Greater Boston Parent to Parent
1505 Commonwealth Ave
Boston, MA 02135
(617) 783-3900

National Tay-Sachs & Allied Diseases Association
2001 Beacon St
Brookline, MA 02146
(800) 906-8723
(617) 277-4463
(617) 277-0134 (fax)

Family Ties of Massachusetts
Dept of Public Health
180 Beaman St
W Boylston, MA 01583
(508) 792-7880
(508) 792-7706 (fax)

MICHIGAN

Family Support Network of Michigan*
MDPH/CSHCS
1200 6th St
9th Fl, N Tower
Detroit, MI 48183
(800) 359-3722 (V/TTY)
(313) 256-3684
(313) 256-1844 (fax)

Autism Society of Michigan
809 Center St, Ste 8A
Lansing, MI 48906
(517) 487-9260
(517) 487-2377 (fax)

TRENDS
PO Box 1996
Holland, MI 49422-1996
(616) 392-6307

MINNESOTA

Pilot Parents of NE Minnesota
201 Ordean Bldg
Duluth, MN 55802
(218) 726-4725
(218) 726-4722 (fax)

The Windmill Project
Lakes Country Service Cooperative
1001 E Mt Faith
Fergus Falls, MN 56537
(218) 739-3273
(218) 739-2459 (fax)

People to People
Rte 2, Box 145
Owatonna, MN 55060-9624
(507) 451-4585

Family Liaison Project
Arc of Olmstead Cty
903 W Center St, #140
Rochester, MN 55902
(507) 287-2032
(507) 287-2063 (fax)

Midstate Pilot Parents
PO Box 1536
St Cloud, MN 56302
(612) 253-6844
(612) 253-6844 (fax)

Pilot Parents
425 Etna St, #36
St Paul, MN 55106
(612) 778-0727 (V/TTY)
(612) 778-0449 (fax)

Parents for Parents
280 N Smith Ave, Ste 245
St Paul, MN 55102
(612) 220-6731

Veteran Parents
280 N Smith, Ste 245
St Paul, MN 55102
(612) 220-6731

Turner's Syndrome Society of the US
811 Twelve Oaks Ctr
15500 Wayzata Blvd
Wayzata, MN 55391
(612) 475-9944
(612) 475-9949 (fax)

MISSISSIPPI

Mississippi Gulf Coast Exceptional Parents
PO Box 271
Hurley, MS 39555
(601) 588-2260

MISSOURI

Parents Helping Parents
Kirksville Regional Ctr
1702 E LaHarpe
Kirksville, MO 63501
(800) 621-6082
(816) 785-2500
(816) 785-2520 (fax)

Pilot Parents Program
PO Box 10984
Springfield, MO 65808-0984
(417) 831-0648 (voice/fax)

Positive Parenting Partners
United Services
4140 Old Mill Pkwy
St Peters, MO 63376
(314) 926-2700
(314) 447-4919 (fax)

Keeping Individuals With Developmental Disabilities Services
Rt 3, Box 441
Warsaw, MO 65355
(816) 438-6990

MONTANA

PLUK: Parents, Let's Unite For Kids
MSU-B/SPED 267
1500 N 30th St
Billings, MT 59101
(800) 222-7585 (MT only)
(406) 657-2055
(406) 657-2061 (fax)

Quality Life Concepts
PO Box 2506
Great Falls, MT 59403
(406) 452-9531
(406) 453-5930 (fax)

Parents of Children With Special Needs Support Group
University of Montana
University Hall, 004
Missoula, MT 59812
(406) 243-5344
(406) 243-2797 (fax)
coteach@selway.umt.edu

NEBRASKA

Exceptional Parents Night Out Parent Support Group
318 S Clark
Grand Island, NE 68801
(308) 385-5925

Chris Meyer, 4, really knows how to bring the house down. He's shown here performing in his first piano recital, where he wowed a hometown crowd of 80 in Orlando, Florida. His mom Linda is also his proud teacher. She says his favorite piece is the "choo choo" song—because he loves trains so much. Chris, now 5, attends an inclusive preschool. He has 18 p- syndrome, a chromosomal disorder affecting his speech, growth, teeth and muscle tone.

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Parent Assistance Network
310 W 24th
Kearney, NE 68847
(308) 237-6025
(308) 237-6014 (fax)

Parents Encouraging Parents
Nebraska Dept of Education
301 Centennial Mall S
Lincoln, NE 68509-4987
(402) 471-2471 (V/TTY)
(402) 471-0117 (fax)

Individual & Family Support Services
The Arc of Lincoln
& Lancaster Ctys
215 Centennial Mall S, #410
Lincoln, NE 68508
(402) 477-6925
(402) 477-6927 (fax)

Pilot Parents Program
3610 Dodge St, Ste 101
Omaha, NE 68131
(402) 346-5220
(402) 346-5253 (fax)
aadamson@nnccf.unl.edu

NEVADA

Nevada Association for the Handicapped
Family Support Ctr
6200 W Oakey Blvd
Las Vegas, NV 89102
(702) 870-7050
(702) 870-7649 (fax)

Nevada Parent Network
REPC, College of Education/285
University of Nevada, Reno
Reno, NV 89557-0082
(800) 216-7988 (V/TTY)
(702) 784-4921 (V/TTY)
(702) 784-4997 (fax)
cdinnell@scs.unr.edu

NEW HAMPSHIRE

Parent to Parent of the North Country
69 Willard St
Berlin, NH 03570
(800) 771-8531 (NH only)
(603) 752-8531
(603) 752-3758 (fax)

Parent to Parent of Concord Area
Reg IV Developmental Services
81 Hall St
Concord, NH 03301
(603) 225-4153

Parent to Parent of Strafford County
Forum Ct
113 Crosby Rd, Ste 1
Dover, NH 03820-4375
(603) 749-4015

Parent to Parent of New Hampshire*
PO Box 622
Hanover, NH 03755
(800) 698-5465 (NH only)
(603) 488-6393

Parent to Parent of the Upper Valley
PO Box 622
Hanover, NH 03755
(800) 698-5465 (NH only)
(603) 488-6393

Parent to Parent of the Monadnock Area
640 Marlboro St
Keene, NH 03431-4026
(603) 352-1304

Parent to Parent of the Lakes Region
61 Beacon St W
Laconia, NH 03246
(603) 524-7755

Parent to Parent of Greater Manchester
132 Titus Ave
Manchester, NH 03103
(603) 666-6521

Parent to Parent of Greater Nashua
Ste 22, Harris Pond
32 Daniel Webster Hwy
Merrimack, NH 03054
(603) 882-6333

Parent to Parent of Greater Nashua
144 Canal St
Nashua, NH 03060
(603) 882-6333
(603) 889-5460 (fax)

Parent to Parent of the Seacoast Area
Parade Office Mall, Ste 40
Portsmouth, NH 03801
(800) 660-4103 (NH only)
(603) 436-6111

NEW JERSEY

Support Parents
Arc Bergen Passaic Ctys
223 Moore St
Hackensack, NJ 07601
(201) 343-0322
(201) 343-0401 (fax)

Down Syndrome Parent to Parent
Arc of Essex County
7 Regent St
Livingston, NJ 07039
(201) 535-1181, ext 1224
(201) 535-4314 (fax)

DES Third Generation Network
PO Box 328
Mahwah, NJ 07430

The Arc Developmental Day Care
The Arc Early Intervention Program
The Arc Special Needs
Adaptive Preschool
PO Box 123
Morris Plains, NJ 07950
(201) 765-9661
(201) 540-9224 (fax)

The Sturge-Weber Foundation
PO Box 418
Mt Freedom, NJ 07970
(201) 895-4445
(201) 895-4846 (fax)

National Urea Cycle Disorders Foundation
PO Box 32
Sayreville, NJ 08872
(800) 386-8233

NEW MEXICO

Parents for Behaviorally Different Children
1720 Louisiana NE, Ste 204
Albuquerque, NM 87110
(800) 273-7232 (NM only)
(505) 265-0430
(505) 256-3184 (fax)

Parents of Preterm Infants Network
University of New Mexico Hospital
Dept of Pediatrics, Div of Neonatology—ACC3-3
2211 Loomas NE
Albuquerque, NM 87131
(505) 272-3946
(505) 272-6845 (fax)

Parents Reaching Out*
1000 A Main St
Los Lunas, NM
(800) 524-5176 (V/TTY)
(505) 865-3700 (V/TTY)
(505) 865-3737 (fax)

NEW YORK

Association for Children with Down Syndrome
2616 Martin Ave
Bellmore, NY 11710-3196
(516) 221-4700
(516) 221-4311 (fax)

Parent to Parent of New York State, Long Island
PO Box 236
Blue Point, NY 11715
(516) 363-7227

Newborn and Family Support Services Network
N Central Bronx Hospital
3424 Kossuth Ave
Bronx, NY 10467
(718) 519-4796
(718) 519-4797
(718) 519-5089 (fax)

Parent to Parent of New York State, Metropolitan NYC Region
2 Metro Tech Ctr, Ste 5700
Brooklyn, NY 11201
(800) 405-8818
(718) 834-8217
(718) 238-0530 (fax)

Headway for Brain Injured
856 Ridge Rd
Buffalo, NY 14218
(716) 822-2261
(716) 822-6650 (fax)

Parent to Parent of New York State, Western Region
452 Delaware Ave
Buffalo, NY 14202-1515
(800) 305-8813 (NY only)
(716) 885-1004
(716) 885-3527 (TTY)
(716) 885-9597 (fax)

Parents of Special Children
2 Tower Dr, Ste C
Fulton, NY 13069
(315) 598-7672

National MPS Society
17 Kraemer St
Hicksville, NY 47591
(516) 931-6338
(516) 822-2041 (fax)

Parent to Parent of New York State, S Central Region
Family Resource Network
Box 233
Oneonta, NY 13820
(800) 305-8814
(607) 432-0001
(607) 432-5516 (fax)

Parent Assistance Committee on Down Syndrome
208 Lafayette Ave
Peeksville, NY 10566
(914) 739-4085

St Charles Educational & Therapeutic Center
501 Myrtle Ave
Port Jefferson, NY 11777
(516) 331-6400
(516) 331-6865 (fax)

Prader-Willi Forum
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682

Parent to Parent of New York State*
500 Balltown Rd
Schenectady, NY 12304
(800) 305-8817 (for parents)
(518) 381-4350
(518) 381-4370 (fax)

Parent to Parent of New York State, NYC
930 Willowbrook Rd, Bldg E
Staten Island, NY 10314
(718) 983-5272

Parent to Parent of New York State, N Central Region
Exceptional Family Resources
731 James St, Ste 311
Syracuse, NY 13203
(800) 305-8815
(315) 478-1462
(315) 478-1467 (fax)

Parent to Parent of New York State, Hudson Valley
Family Connection
121C Cedarwood Hall/WHD
Valhalla, NY 10595
(800) 305-8816
(914) 285-1343
(914) 285-1341 (fax)

Parent to Parent
239 Champion Ave
Webster, NY 14580
(716) 265-3778

NORTH CAROLINA

Family Support Network of the Sandhills
PO Box 1268
Biscoe, NC 27209
(910) 428-2892

Parent to Parent/Family Support Network of the High Cty
Appalachian State University
Dept of LRE
Edwin Duncan Hall
Boone, NC 28608
(704) 262-6089
(704) 262-2128 (fax)
klh1988@med.unc.edu

Family Support Network of North Carolina*
UNC—Chapel Hill, CB#7340
Chapel Hill, NC 27599
(800) 852-0042 (V/TTY)
(919) 966-2841

Family Support Network of Orange, Durham & Chatham Ctys
115 Market St, Ste 201
Durham, NC 27701
(919) 560-5600
(919) 560-3018 (fax)

FSN/Parents in Partnership
1623 N Webb St School
Gastonia, NC 28052
(800) 712-2133 (NC only)
(704) 854-4839

Family Support Network of Greater Greensboro
801 Green Valley Rd
Greensboro, NC 27408
(910) 574-6507
(910) 574-6502 (fax)

Family Support Network of Eastern North Carolina
DEC, Irons Bldg, ECU Campus
Greenville, NC 27858
(800) 376-4494
(919) 328-4494
(919) 328-4486 (fax)

Family Support Network/HOPE
Western Carolina Ctr
300 Enola Rd
Morganton, NC 28655
(704) 433-2661
(704) 438-6457 (fax)

Family Support Network of SE North Carolina
1501 Dock St
Wilmington, NC 28401
(910) 251-5817, ext 235
(910) 251-2652 (fax)

Parents Together
4505 Shattalon Dr
Winston-Salem, NC 27106
(910) 924-5301
(910) 924-0388 (fax)
abf@med.unc.edu

OHIO

Down Syndrome Association of Greater Cincinnati
1821 Summit Rd, Ste 102
Cincinnati, OH 45237-2818
(513) 761-5400
(513) 761-5401 (fax)

Ohio Protection & Advocacy Association
4030 Mt Carmel/Tabasco, Ste 214
Cincinnati, OH 45255
(800) 597-7690 (OH only)
(513) 528-4690

Ohio Protection & Advocacy Association
5030 Brookpark Rd
Cleveland, OH 44134
(800) 672-1220 (OH only)
(216) 398-5501
(216) 398-5505 (fax)

Family Information Network*
246 N High St, 5th Fl
Columbus, OH 43215
(614) 644-9165
(614) 644-8661 (fax)

Ohio Head Injury Association
1335 Dublin Rd, Ste 50A
Columbus, OH 43215-1000
(800) 686-9563 (OH only)
(614) 481-7100
(614) 481-7103 (fax)
aroeble@freenet.columbus.oh.us

Celebrating Families of Children and Adults with Special Needs
16 Vassar Dr
Dayton, OH 45406
(513) 275-0990 (voice/fax)

Miami Valley Down Syndrome Association
1444 Beaver Creek Ln
Kettering, OH 45429-3704
(513) 294-1240

Family Information Network
1 Stranahan Sq, #540
Toledo, OH 43604
(419) 242-9587, ext 105 or 125
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(503) 343-0652 (fax)

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Medford, OR 97504
(800) 422-6428
(503) 770-4233

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Salem, OR 97303-5299
(503) 373-7477 (V/TTY)

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Edinboro, PA 16412
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(814) 734-5806 (fax)

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(412) 837-7453 (fax)

Down Syndrome Support Group of Lancaster Cty
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25 NW End Ave
Lancaster, PA 17603
(717) 898-2656

Down Syndrome Support Group of Lancaster Cty
465 Long Rd
Manheim, PA 17545
(717) 898-2656

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Upland, PA 19015
(800) 606-2682

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Newtown Square, PA 19703
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Williamsport, PA 17701
(717) 321-2660
(717) 321-2057 (fax)

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Down Syndrome Society of Rhode Island
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(915) 691-7345 (fax)

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Wee-Life Parents
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Racine, WI 53403
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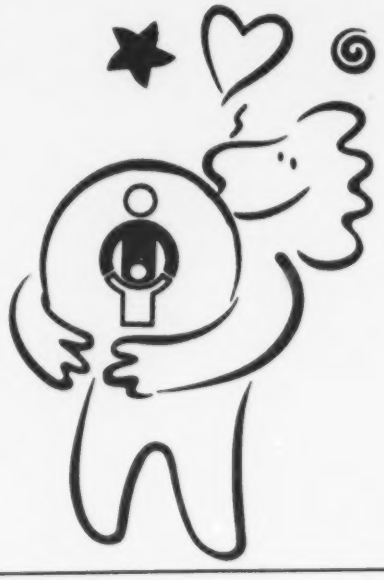

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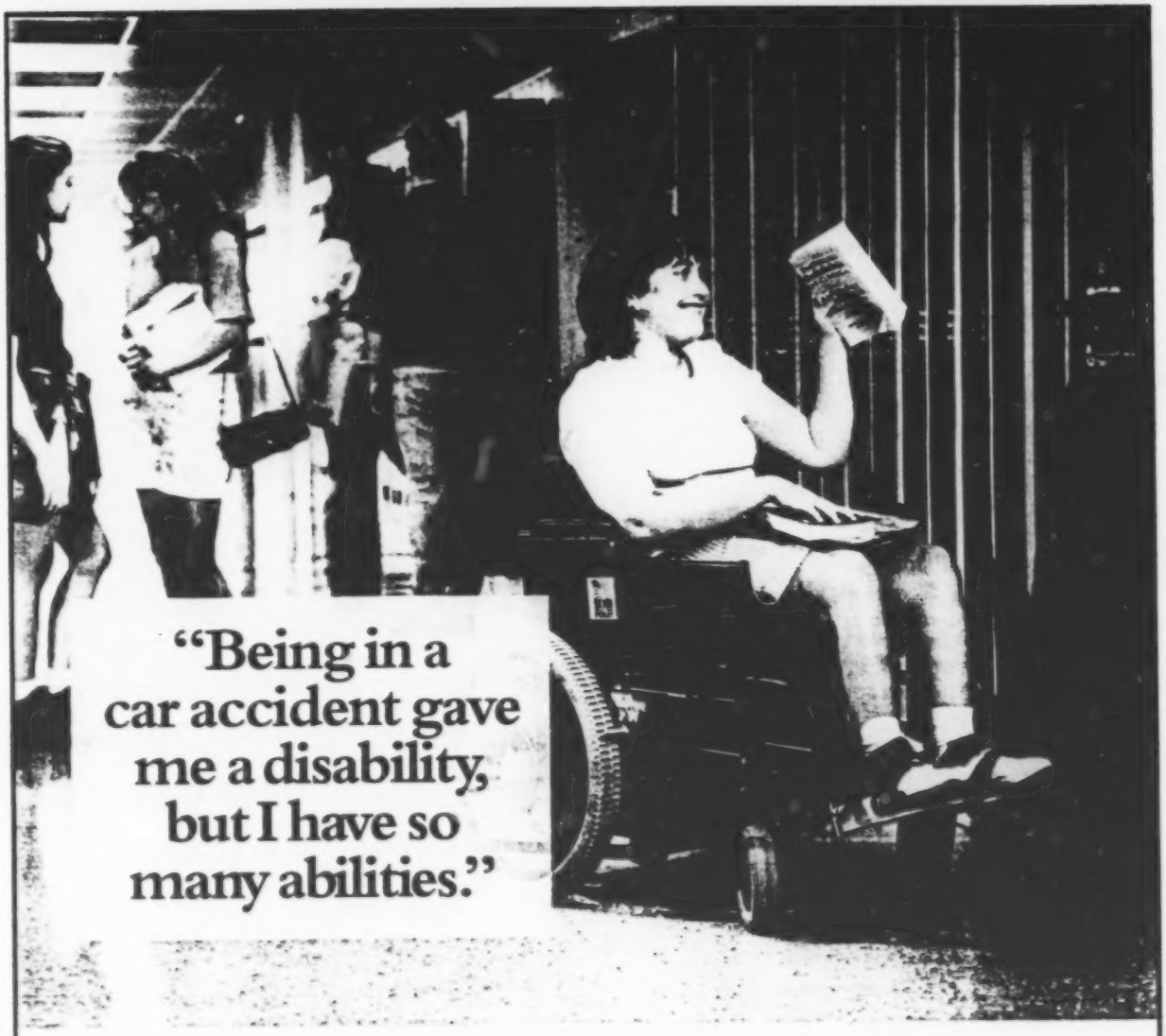

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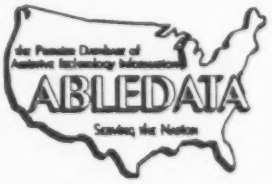

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CONDUCTED BY
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Eileen Eller-Miller, M.A., CCC
Laurie E. Smith, M.Ed.

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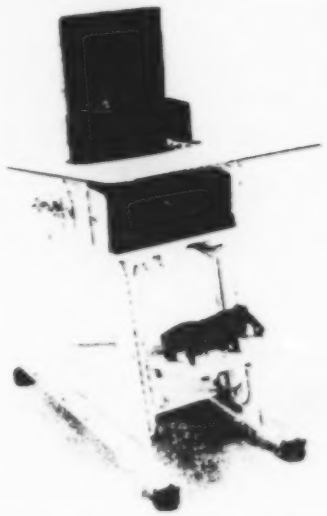

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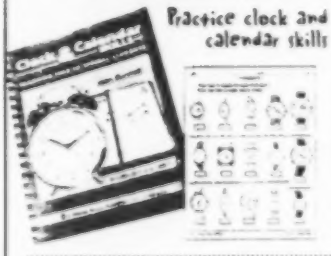

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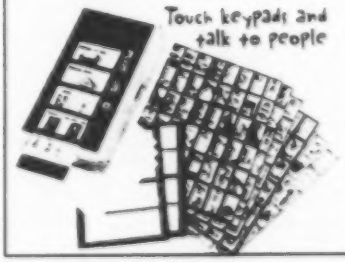

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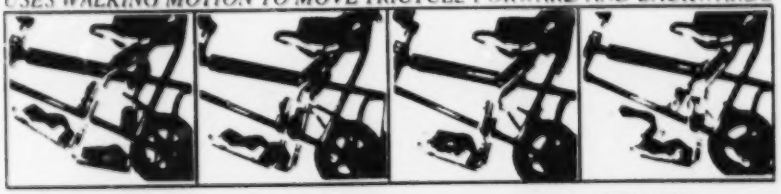

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Intensive Program

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For more information on our Intensive Program, please contact **Catherine M. Welch, MEd, Director of Admissions.**

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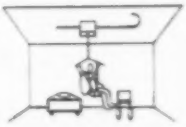

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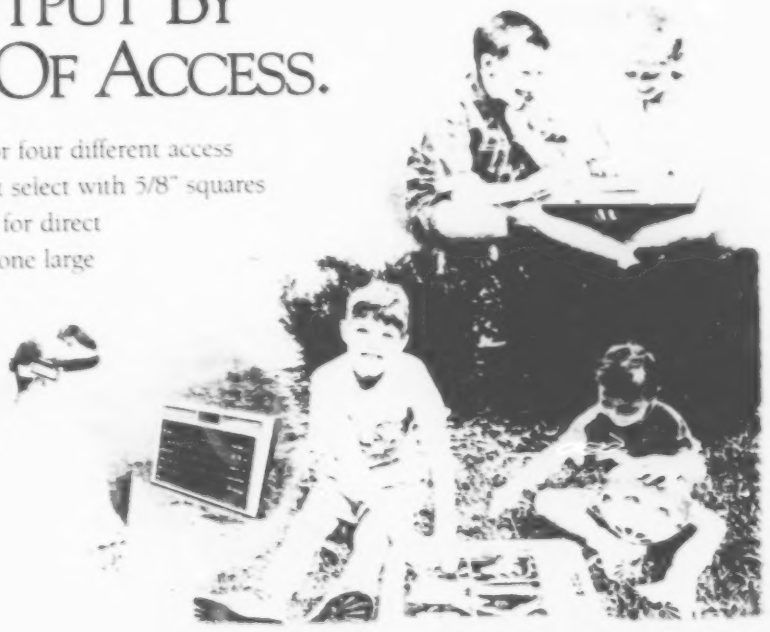

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The Alliance for Technology Access (ATA) began in 1987 as a joint project of a grass-roots organization—Disabled Children's Computer Group—and a major corporation—Apple Computer.

From this small group of parents, consumers and professionals, the ATA has grown into one of the nation's largest resources to help adults and children with disabilities gain access to the benefits of adaptive technology.

The ATA's most important means of promoting technology access may be its nationwide network of community-based assistive technology resource centers. ATA centers work with a wide variety of individuals and organizations and have no eligibility criteria for determining who may receive services. Most centers provide hands-on consultations and product demonstrations, make recommendations and referrals, and present workshops on technology use.

This symbol (✉) indicates an internet e-mail address; when available. World Wide Web sites are also listed.

ALABAMA

Birmingham Alliance for Technology Access Center
Birmingham Independent Living Center
206 13th St S
Birmingham, AL 35233-1317
(205) 251-2223 (V/TTY)
(205) 251-0605 (fax)
✉ bilcala@aol.com
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Technology Assistance for Special Consumers
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(205) 532-5994 (fax)
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ALASKA

Alaska Services For Enabling Technology
207 Moller Dr
PO Box 6485
Sitka, AK 99835
(907) 747-7615 (voice)
✉ asetseak@aol.com
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ARIZONA

Technology Access Center of Tucson
4710 E 29th St
PO Box 13178
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(520) 745-5583, ext 412 (voice)
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Technology Resource Center
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(415) 961-6775 (fax)
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Anaheim, CA 92805
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(714) 533-2533 (fax)
✉ taskca@aol.com
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CITE (Center for Independence, Technology and Education)
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✉ tekablega1@aol.com
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(808) 523-5547 (voice)
(808) 523-5548 (fax)
✉ stachi@aol.com
http://www.aloha.net/~stachi/
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ILLINOIS

Northern Illinois Center for Adaptive Technology
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Rockford, IL 61108-6195
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(815) 229-2135 (fax)
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MASSACHUSETTS

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(617) 275-2446 (voice)
✉ mastacma@aol.com
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Living & Learning Resource Centre
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Lansing, MI 48906-5038
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(517) 487-0883 (V/TTY)
(517) 487-1605 (fax)
✉ llrcmi@aol.com
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MINNESOTA

PACER Computer Resource Center
4826 Chicago Ave S
Minneapolis, MN 55417-1098
(612) 827-2966 (V/TTY)
(612) 827-3065 (fax)
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MISSOURI

Technology Access Center
12110 Clayton Rd
St Louis, MO 63131-2599
(314) 569-8404 (voice)
(314) 569-8446 (TTY)
(314) 993-5937 (fax)
✉ mostltac@aol.com
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MONTANA

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MSU-B/SPED Bldg, Rm 267
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Billings, MT 59101-0298
(406) 657-2055 (V/TTY)
(406) 657-2061 (fax)
✉ plukmt@aol.com
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NEW JERSEY

Center for Enabling Technology
622 Route 10 W, Ste 22B
Whippany, NJ 07981-0272
(201) 428-1455 (voice)
(201) 428-1450 (TTY)
✉ cetnj@aol.com
1,2,3,12,13,15,16; open resource hours

Computer Center for People with disAbilities
35 Haddon Ave
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(908) 747-5310 (voice)
(908) 747-5936 (fax)
✉ ccdanj@aol.com
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KEY TO SERVICES

1 Hands-on technology demonstrations
2 Guided exploration and problem-solving
3 Formal technology-needs assessments
4 Assistance in obtaining assistive technology funding
5 Software lending library
6 Loans of computers and hardware
7 Loans of assistive devices
8 Toy lending library
9 Videotape lending library
10 Constructing/adapting switches and devices
11 Technical assistance to IEP teams
12 Teacher training
13 Parent/family training
14 Augmentative communication training
15 Workshops
16 Early childhood/preschool programs
17 Computer camps and/or after-school programs
18 Transition training for young adults
19 Technical assistance to employers
20 Newsletter

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Resource Center
for Independent Living
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(315) 797-5837 (TTY)
(315) 797-4747 (fax)
✉ bprsnyc@aol.com
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NORTH CAROLINA

Carolina Computer Access Center
Metro School
700 E Second St
Charlotte, NC 28202-2826
(704) 342-3004 (voice)
(704) 342-1513 (fax)
✉ ccacnc@aol.com
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OHIO

Technology Resource Center
301 Valley St
Dayton, OH 45404-1840
(513) 222-5222 (voice)
(513) 222-2101 (fax)
✉ trcdoh@aol.com
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If clothes make the man, do they also make the little sister? Two-year-old **Mackenzie Maroney** loves to play dress up—even with her big brother's baseball cap! Mackenzie lives in Parker, Colorado with her parents, Dianne and Jim, and brothers Michael, 8, and Frankie, 6. Mackenzie, who was born three and a half months prematurely, has chronic lung disease and developmental delays.

RHODE ISLAND

TechACCESS Center of Rhode Island
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(800) 916-8324 (V/TTY; RI only)
(401) 273-1990 (V/TTY)
(401) 831-1131 (fax)
✉ accessri@aol.com
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TENNESSEE

East Tennessee Technology Access Center
3525 Emory Rd NW
Powell, TN 37849
(423) 947-2191 (V/TTY)
(423) 947-2194 (fax)
✉ etstactn@aol.com
1,2,3,4,5,6,7,8,9,10,11,12,13,14, 15,16,17,18,19,20

Technology Access Center of Middle Tennessee
2222 Metro Center Blvd, Ste 126
Nashville, TN 37228
(800) 368-4651 (V/TTY)
(615) 248-6733 (V/TTY)
(615) 259-2536 (fax)
✉ tactn@aol.com
1,2,3,4,6,7,9,11,12,13,14,15,19,20

West Tennessee Special Technology Access Resource Center (STAR Center)
60 Lynoak Cove
Jackson, TN 38305
(901) 668-3888 (voice)
(901) 668-1666 (fax)
✉ startn@aol.com
1,2,3,4,5,6,7,10,11,12,13,14,15,1 6,17,18,19,20; mobile unit provides services in rural areas

UTAH

Computer Center for Citizens with Disabilities
2056 S 1100 E
Salt Lake City, UT 84106
(801) 485-9152 (V/TTY)
(801) 485-8675 (fax)
✉ cccdutr@aol.com
1,2,9,12,14,15; provides low-cost public domain software

VIRGIN ISLANDS

Virgin Islands Resource Center for the Disabled
PO Box 308427
St Thomas, USVI 00803-8427
(809) 777-2253 (voice)
(809) 774-5816 (fax)
1,2,12,15,17,18,19,20

VIRGINIA

Tidewater Center for Technology Access
Special Education Annex
960 Windsor Oaks Blvd
Virginia Beach, VA 23462
(804) 474-8650 (V/TTY)
(804) 474-8648 (fax)
✉ tcta@aol.com
1,2,3,4,5,6,7,8,9,11,12,13,14,15, 16,17,18,19,20

WEST VIRGINIA

Eastern Panhandle Technology Access Center
PO Box 987
Charles Town, WV 25414
(304) 725-6473 (voice)
(304) 728-4814 (fax)
✉ eptac@aol.com
1,2,4,5,6,7,9,10,11, 12,13,15,18,1

CANADA

Alliance Centre for Technology
360 George St N, Ste 202
Peterborough, ON CAN K9J 7E7
(705) 741-4214 (V/TTY)
(705) 741-4581 (fax)
✉ alliance@trentu.ca
1,2,3,4,5,7,9,10,11,13,15,18,19,20; basic computer exploration course, at-home services when needed

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Fax (610) 584-4151

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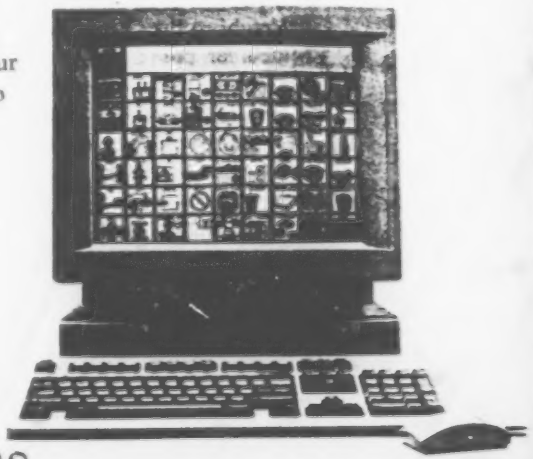

Sentient Systems *Technology, Inc.*

Circle #110

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State Assistive Technology Programs

The following state assistive technology programs are funded by the National Institute on Disability and Rehabilitation Research (NIDRR) under the Technology-Related Assistance For Individuals With Disabilities Act of 1988 (and Amendments of 1994). For more information, contact the RESNA Technical Assistance Project, 1700 North Moore St., Ste. 1540, Arlington, VA 22209-1903; (703) 524-6686, voice; (703) 524-6630, TTY.

A description of services provided by individual programs follows each listing. Numbers correspond to items listed in the Key to Services. This symbol (✉) indicates an Internet e-mail address; when available, World Wide Web sites are also listed.

ALABAMA

Statewide Technology Access and Response System for Alabamians with Disabilities
2125 E South Blvd
PO Box 20752
Montgomery, AL 36120-0752
(334) 613-3480 (voice)
(334) 613-2519 (TTY)
(334) 613-3485 (fax)
1,2,3,4,5

ALASKA

Assistive Technologies of Alaska
701 E Tudor Rd, Ste 280
Anchorage, AK 99503-7445
(800) 770-0138 (voice)
(800) 898-0138 (TTY)
(907) 563-0318 (V/TTY)
(907) 563-0146 (fax)
✉ atadvr@cor.com
1,2,3,4,5,6,7,8

AMERICAN SAMOA

Assistive Technology Project
Division of Vocational Rehabilitation
Dept of Human Resources
PO Box 4561
Pago Pago, American Samoa 96799
(684) 699-1371 (voice)
(684) 699-1376 (fax)
1,3,5,8; school-to-work transition program, community integration activities

ARIZONA

Arizona Technology Access Program
2600 N Wyatt Dr, 2nd Fl
Tucson, AZ 85712
(520) 324-3170 (voice)
(520) 324-3177 (TTY)
(520) 324-3176 (fax)
✉ demetras@ccit.arizona.edu
1,2,5,8

ARKANSAS

Increasing Capabilities Access Network
2201 Brookwood, Ste 117
Little Rock, AR 72202
(800) 828-2799 (V/TTY; AR only)
(501) 666-8868 (V/TTY)
(501) 666-5319 (fax)
1,2,3,4,5,6,7,8

CALIFORNIA

California Assistive Technology System
CA Dept of Rehabilitation
830 K St
Sacramento, CA 95814
(800) 390-2699 (V/TTY; CA only)
(916) 324-3062 (V/TTY)
(916) 324-7386 (TTY)
(916) 323-0914 (fax)
✉ doroa.smentkow@hw1.cahwnet.gov
1,7; newsletter

COLORADO

The Colorado Assistive Technology Program
Rocky Mountain Resource and Training Institute
1391 N Speer Blvd, Ste 350
Denver, CO 80204
(800) 255-3477 (V/TTY; CO only)
(303) 534-1027 (V/TTY)
(303) 534-1075 (fax)
✉ rmrti@essex.uchsc.edu
1,3

CONNECTICUT

Assistive Technology Project
Bureau of Rehabilitation Services
10 Griffin Rd N
Windsor, CT 06095
(860) 298-2042 (voice)
(860) 298-2018 (TTY)
(860) 298-9590 (fax)
✉ jficarro@aol.com
1,2,5,7

DELAWARE

Delaware Assistive Technology Initiative
University of Delaware
Al duPont Institute
1600 Rockland Rd, Rm 154
Wilmington, DE 19899
(302) 651-6790 (voice)
(302) 651-6794 (TTY)
(302) 651-6793 (fax)
✉ dati@asel.udel.edu
1,2,3,4,5,6,8

DISTRICT OF COLUMBIA

Partnership for Assistive Technology
801 Pennsylvania Ave SE, Ste 210
Washington, DC 20003
(202) 546-9163 (voice)
(202) 546-9168 (TTY)
(202) 546-9169 (fax)
✉ alexlugo@dcpat.org
1,3,5; community outreach, consumer focus group, adaptive toy workshops

FLORIDA

Alliance for Assistive Service and Technology
2002 Old St Augustine Rd, Bldg A
Tallahassee, FL 32399-0696
(800) 322-7881 (voice)
(904) 487-3278 (V/TTY)
(904) 921-7214 (fax)
✉ faast@freenet.scri.fsu.edu
1,3,6

GEORGIA

Tools for Life
Division of Rehabilitation Services
2 Peachtree St NW, Ste 23-411
Atlanta, GA 30303
(800) 497-8665 (voice; GA only)
(404) 657-3084 (V/TTY)
(404) 657-3085 (TTY)
(404) 657-3086 (fax)
✉ 102476.1737@compuserve.com
1,2,3,4,5,6,8

HAWAII

Assistive Technology Training and Services
677 Ala Moana Blvd, Ste 403
Honolulu, HI 96813
(808) 532-7110 (V/TTY)
(808) 532-7120 (fax)
✉ bfl@pixi.com
1,2,3,4,5,7

IDAHO

Assistive Technology Project
129 W Third St
Moscow, ID 83843
(208) 885-3630 (voice)
(800) 432-8324 (V/TTY; ID only)
(208) 885-3628 (fax)
1,2,3,4,5,6,7

ILLINOIS

Assistive Technology Project
528 S 5th St, Ste 100
Springfield, IL 62701
(800) 852-5110 (V/TTY; IL only)
(217) 522-7985 (V/TTY)
(217) 522-8067 (fax)
✉ ilatp@gteens.com
1,2,3,4,5,6

INDIANA

ATTAIN: Accessing Technology Through Awareness in Indiana Project
PO Box 7083
402 W Washington St, Rm W453
Indianapolis, IN 46207-7083
(800) 545-7763 (V/TTY)
(317) 232-1410 (V/TTY)
(317) 232-6478 (fax)
1,2,5,6,8,9

IOWA

Iowa Program for Assistive Technology
Iowa University Affiliated Program
University Hospital School
Iowa City, IA 52242-1011
(800) 348-7193 (V/TTY)
(319) 356-4382 (V/TTY)
(319) 356-8284 (fax)
1,2,5,6,8; newsletter

KANSAS

Assistive Technology for Kansans Project
2601 Gabriel
PO Box 738
Parsons, KS 67357
(316) 421-8367 (voice)
(316) 421-0954 (TTY)
(316) 421-0954 (fax)
✉ ssimmons@parsons.isi.ukans.edu
1,2,3,4,5,6,7,8; statewide technology conferences

KENTUCKY

Assistive Technology Services Network
PO Box 757
Frankfort, KY 40602-0757
(800) 327-5287 (voice)
(502) 564-2733 (V/TTY)
(502) 564-2951 (fax)
1,2,3,4,5,6

LOUISIANA

Louisiana Assistive Technology Access Network
PO Box 14115
Baton Rouge, LA 70898-4115
(800) 270-6185 (V/TTY)
(504) 925-9500 (V/TTY)
(504) 925-9560 (fax)
✉ latanstate@aol.com
1,2,3,5; assistive technology assessment; consumer empowerment training, conferences, workshops

MAINE

Consumer Information and Technology Training Exchange
Maine CITE Coordinating Ctr
Education Network of Maine
46 University Dr
Augusta, ME 04330
(207) 621-3195 (V/TTY)
(207) 621-3193 (fax)
✉ kpowers@maine.caps.maine.edu
1,2,4,5,7,8

MARYLAND

Technology Assistance Program
Governor's Office for Individuals with Disabilities
300 W Lexington St, Box 10
Baltimore, MD 21201
(800) 832-4827 (V/TTY)
(410) 333-4975 (V/TTY)
(410) 333-6674 (fax)
✉ mbrady@epfl1.epflbalto.org
1,2,3,4,5

MASSACHUSETTS

Massachusetts Assistive Technology Partnership Center
Children's Hospital
1295 Boylston St, Ste 310
Boston, MA 02215
(800) 848-8867 (V/TTY; MA only)
(617) 355-7820 (voice)
(617) 355-7301 (TTY)
(617) 355-6345 (fax)
(800) 950-6287 (2400-baud BBS, MA only)
(617) 267-5027 (2400-baud BBS)
✉ brewer_ju@a1.tch.harvard.edu
1,2,5

MICHIGAN

Tech 2000
PO Box 30010
Lansing, MI 48909-7510
(517) 373-9233 (voice)
(517) 373-4035 (TTY)
(517) 373-0565 (fax)
✉ mbarnes@match.org
2,8

MINNESOTA

Star Program
300 Centennial Bldg
658 Cedar St
St Paul, MN 55155
(612) 296-9478 (voice)
(612) 296-9962 (TTY)
(612) 297-7200 (fax)
✉ mnstars@gteens.com
1,2,9

MISSISSIPPI

Project Start
PO Box 1000
Jackson, MS 39205-1000
(800) 852-8328 (V/TTY; MS only)
(601) 853-5171 (V/TTY)
(601) 853-5158 (fax)
✉ mspjtstr@gteens.com
1,2,3,4,5,6,7,8,9

MISSOURI

Assistive Technology Project
4731 S Cochise, Ste 114
Independence, MO 64055-6975
(816) 373-5193 (voice)
(816) 373-9315 (TTY)
(816) 373-9314 (fax)
✉ matpmo@accunet.com
1,2,3,5,6,7,8

KEY TO SERVICES

1. Information and referral
2. Assistance in obtaining funding for devices, services
3. Equipment demonstration center
4. Equipment loan program
5. Training
6. Equipment exchange and recycling program
7. Loan program for the purchase of assistive technology, services
8. Peer support groups
9. Mobile van outreach

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STATE ASSISTIVE TECHNOLOGY PROGRAMS

MONTANA

Montech
University of Montana
MUARID: MonTECH
634 Eddy Ave
Missoula, MT 59812
(800) 732-0323 (V/TTY)
(406) 243-4730 (fax)
(800) 961-9610 (BBS: MT only)
(406) 243-2318/2319 (BBS)
leechi@selway.umt.edu
1,2,3,4,5,6,8

NEBRASKA

Assistive Technology Project
301 Centennial Mall S
PO Box 94987
Lincoln, NE 68509-4987
(800) 742-7594 (V/TTY: NE only)
(402) 471-0734 (V/TTY)
(402) 471-0117 (fax)
mschultz@nde4.nde.state.ne.us
1,3,4,5,6,8

NEVADA

Assistive Technology Collaborative
Dept of Employment, Training, & Rehabilitation
Rehabilitation Division
Office of Community Based Services
711 S Stewart St
Carson City, NV 89710
(800) 992-0900, ext 4452 (voice; NV only)
(702) 687-4452 (voice)
(702) 687-3388 (TTY)
(702) 687-3292 (fax)
nvreach@gteens.com
1,2,3,4,5,6,7,9

NEW HAMPSHIRE

Assistive Technology Partnership Project
The Concord Ctr
10 Ferry St, Ste 321, Unit #25
Concord, NH 03301
(800) 427-3338 (V/TTY: NH only)
(603) 228-2088 (V/TTY)
(603) 228-2468 (fax)
mjpawlek@christa.unh.edu
1,2,3,4,5,6,7; regional resource centers

NEW JERSEY

Technology Assistive Resource Program
135 E State St, CN 398
Trenton, NJ 08625
(800) 342-5832 (voice; NJ only)
(800) 382-7765 (TTY: NJ only)
(609) 292-7498 (voice)
(609) 292-8347 (fax)
1,2,3,5,6,8,9

NEW MEXICO

Technology Assistance Program
435 St Michael's Dr, Bldg D
Santa Fe, NM 87505
(800) 866-2253 (voice)
(800) 659-4915 (TTY)
(505) 827-3746 (fax)
nmovrtap@aol.com
1,2,4,5,8,9

NEW YORK

New York State TRAID Project
NYS Office of Advocates for Persons with Disabilities
One Empire State Plaza, Ste 1001
Albany, NY 12223-1150
(518) 474-2825 (voice)
(518) 473-4231 (TTY)
(518) 473-6005 (fax)
d.buck@oapwd.state.ny.us
1,2,3,4,5,6; regional centers

NORTH CAROLINA

Assistive Technology Project
Dept of Human Resources
Division of Vocational Rehabilitation Services
1110 Navaho Dr, Ste 101
Raleigh, NC 27609
(800) 852-0042 (voice)
(919) 850-2787 (V/TTY)
(919) 850-2792 (fax)
atp@med.unc.edu
1,2,3,4,6,8

NORTH DAKOTA

Interagency Program for Assistive Technology
PO Box 743
Cavalier, ND 58220
(800) 451-8693 (V/TTY: info line)
(800) 265-4728 (V/TTY)
(701) 265-4807 (V/TTY)
(701) 265-3150 (fax)
lee@pioneer.state.nd.us
1,2,4,5,6,9

NORTHERN MARIANA ISLANDS

Assistive Technology Project—STRAID
Governor's Developmental Disabilities Council
PO Box 2565
Saipan, MP 96950
(670) 322-3015 (voice)
(670) 322-4168 (fax)
dd.council@saipan.com
1,3,4,5,6

OHIO

TRAIN: Technology-Related Assistance Information Network
Ohio Super Computer Ctr
1224 Kinnear Rd
Columbus, OH 43212
(800) 784-3425 (V/TTY: OH only)
(614) 292-2426 (V/TTY)
(614) 292-5866 (fax)
info@mailear.ovl.osc.edu
1,2,4,6

OKLAHOMA

Oklahoma ABLE Tech
Oklahoma State University
Wellness Center
1514 W Hall of Fame
Stillwater, OK 74078-0618
(800) 257-1705 (V/TTY)
(405) 744-9748 (V/TTY)
(405) 744-7670 (fax)
glenna@okway.okstate.edu
1,2,3,4,5,8

OREGON

Techology Access for Life Needs Project
Oregon Disabilities Commission
1257 Ferry St SE
Salem, OR 97310
(800) 677-7512 (V/TTY: OR only)
(503) 361-0012 (voice)
(503) 378-3599 (fax)
susan.mcnaught@p10.f99.n105.z1.fidonet.org
1,2,3,4,5,6,7,8; regional centers, equipment-adaptation workshops

PENNSYLVANIA

Pennsylvania's Initiative on Assistive Technology
Institute on Disabilities/UAP
Temple University
Ritter Hall Annex 433 (004-00)
Philadelphia, PA 19122
(800) 204-7428 (voice)
(800) 750-7428 (TTY)
(215) 204-9371 (fax)
piat@astro.ocis.temple.edu
1,2,3,4,5,6,8; regional centers

PUERTO RICO

Assistive Technology Project
University of Puerto Rico
Medical Sciences Campus
College of Health-Related Professions
Dept of Communication Disorders
Box 365067
San Juan, PR 00936-5067
(800) 496-6035 (From US mainland)
(800) 981-6033 (PR only)
(809) 754-8034 (TTY)
(809) 759-3645 (fax)
pratp@rcmad.upr.clu.edu
1,2,3,5

RHODE ISLAND

Assistive Technology Access Project
Dept of Human Services
Div of Community Services
Office of Rehabilitation Services
Voc Rehab
40 Fountain St, 5th Fl
Providence, RI 02903-1898
(800) 752-8038, ext 2608 (RI only)
(401) 421-7005 (voice)
(401) 272-8090 (Spanish)
(401) 272-7990 (Khmer)
(401) 421-7016 (TTY)
(401) 274-1920 (fax)
ab195@osfn.rhilinet.gov
1,2,3,4,5,7,8

SOUTH CAROLINA

Assistive Technology Program
Vocational Rehabilitation Dept
PO Box 15, 1410-C Boston Ave
West Columbia, SC 29171-0015
(803) 822-5404 (V/TTY)
(803) 822-4301 (fax)
jgendron@scsn.net
1,2,3,4,5,7,9; public policy advocacy efforts

SOUTH DAKOTA

DakotaLink
1925 Plaza Blvd
Rapid City, SD 57702
(800) 645-0673 (V/TTY: SD only)
(605) 344-1876 (V/TTY)
(605) 394-5315 (fax)
rreed@sdbe.sdserv.org
1,2,3,4,5,6,7,8,9; regional centers

TENNESSEE

Technology Access Project
710 James Robertson Pkwy
Gateway Plaza, 11th Fl
Nashville, TN 37243-0675
(800) 732-5059 (TN only)
(615) 532-6530 (voice)
(615) 532-6612 (TTY)
(615) 532-9940 (fax)
1,2,3,4,5,6,9; regional centers

TEXAS

Texas Assistive Technology Partnership
University of Texas at Austin
Dept of Special Education, SZB 306 D5300
Austin, TX 78712-1290
(800) 828-7839 (voice)
(512) 471-7621 (voice)
(512) 471-1844 (TTY)
(512) 471-7549 (fax)
bbryant@mail.utexas.edu
http://www.edb.utexas.edu/coe/depts/sped/tatp/tatp.html
8

UTAH

Utah Center for Assistive Technology
Center for Persons with Disabilities
UMC 6855
Logan, UT 84322-6855
(800) 333-8824 (V/TTY)
(801) 797-2096 (V/TTY)
(801) 797-2355 (fax)
mmenlove@cc.usu.edu
1,2,3,4,5,6,7; equipment customizing and fabrication

VERMONT

Assistive Technology Project
103 S Main St
Waterbury, VT 05671-2305
(800) 750-6355 (V/TTY: VT only)
(802) 241-2620 (V/TTY)
(802) 241-3052 (fax)
tomf@dad.state.vt.us
1,2,3,4,5,6,7,8

VIRGINIA

Assistive Technology System
8004 Franklin Farms Dr
PO Box K–300
Richmond, VA 23288-0300
(804) 662-9990 (V/TTY)
(804) 662-9478 (fax)
(800) 238-7955 (VA only; 2400-baud BBS)
(804) 662-9477 (2400-baud equipment exchange BBS)
vatskhk@aol.com
1,2,5,6,8; advocacy assistance

WASHINGTON

Washington Assistive Technology Alliance
DSHS/DVR
PO Box 45340
Olympia, WA 98504-5340
(360) 438-8051 (voice/TTY)
(360) 438-8644 (TTY)
(360) 438-8007 (fax)
hooksd@dshs.wa.gov
1,2,3

WEST VIRGINIA

West Virginia Assistive Technology System
Division of Rehabilitation Services
PO Box 50890
Charleston, WV 25305-0890
(800) 841-8436 (voice; WV only)
(304) 293-4692 (V/TTY)
(304) 293-7294 (fax)
reb@wvnvm.wvnet.edu
1,3,4,5

WISCONSIN

WisTech
Division of Vocational Rehabilitation
PO Box 7852
2917 International Ln
Madison, WI 53707-7852
(608) 243-5674 (voice)
(608) 243-5601 (TTY)
(608) 243-5681 (fax)
trampf@aol.com
1,3,4,8

WYOMING

WYNOT: Wyoming's New Options in Technology
Division of Vocational Rehabilitation
1100 Herschler Bldg
Cheyenne, WY 82002
(800) 877-9975 (voice)
(800) 877-9965 (TTY)
(307) 777-7450 (voice)
(307) 777-5939 (fax)
awl13h@wydsprod.state.wy.us
1,2,3,4,5,6

KEY TO SERVICES

1. Information and referral
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3. Equipment demonstration center
4. Equipment loan program
5. Training
6. Equipment exchange and recycling program
7. Loan program for the purchase of assistive technology, services
8. Peer support groups
9. Mobile van outreach

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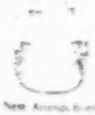

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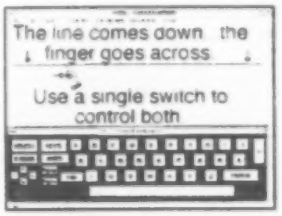

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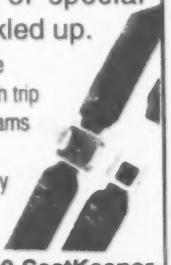

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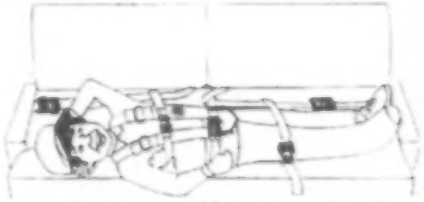

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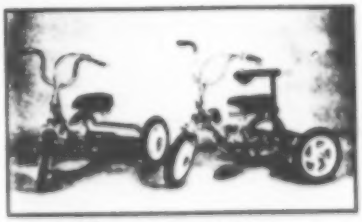

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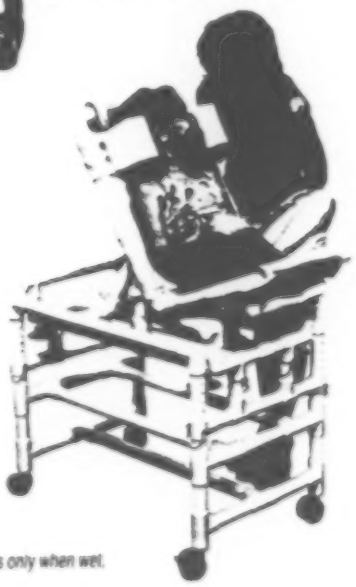

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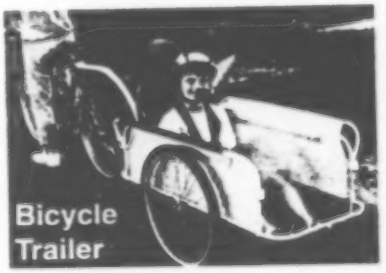

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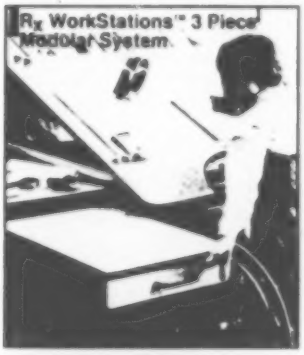

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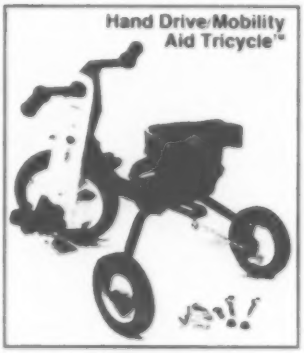

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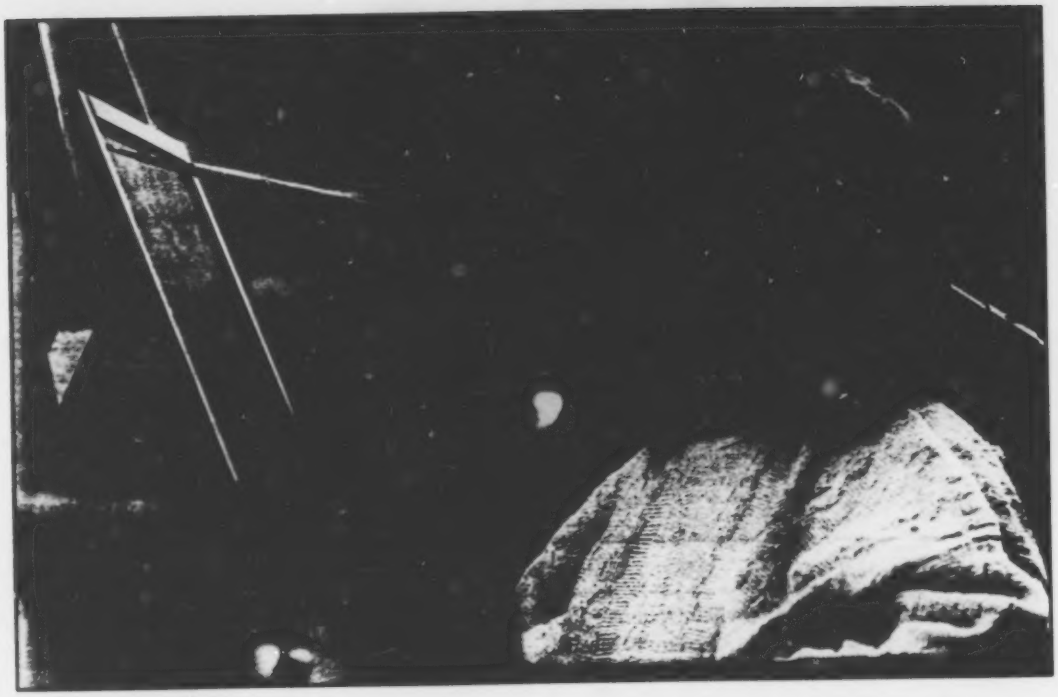

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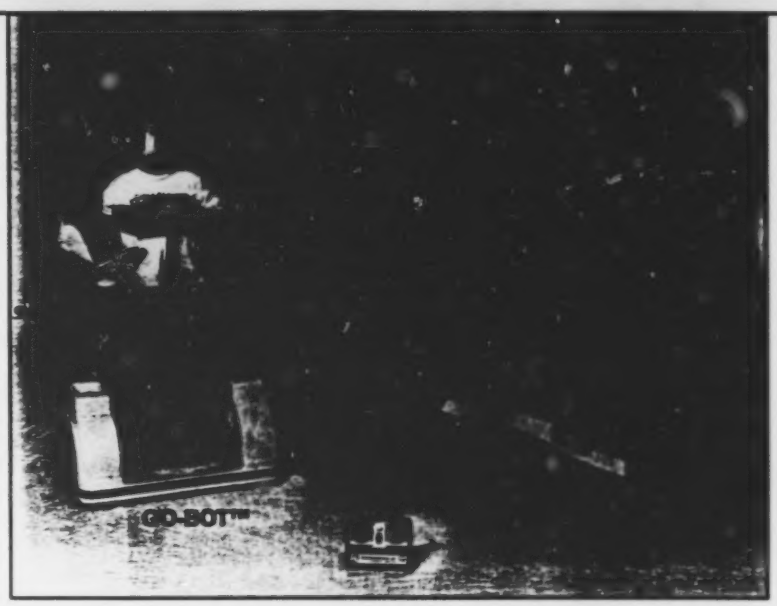
97



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(913) 864-5323 (fax)

Ralph L. Smith Mental Retardation Research Center (R)
Univ of Kansas Medical Ctr
39th & Rainbow Blvd
Kansas City, KS 66103
(913) 588-5970
(913) 588-5677 (fax)

Parsons Research Center (R)
Institute for Life Span Studies
PO Box 738
Parsons, KS 67357
(316) 421-6550
(316) 421-6550, ext 1864

KENTUCKY

Human Development Institute
Univ of Kentucky
126 Mineral Industries Bldg
Lexington, KY 40506-0051
(606) 257-1714
(606) 258-1901 (fax)

LOUISIANA

Human Development Center
School of Allied Health Professions
Louisiana State Univ Medical Ctr
1100 Florida Ave, Bldg 138
New Orleans, LA 70119-2799
(504) 942-8202
(504) 942-8305 (fax)

MAINE

Center for Community Inclusion
5717 Corbett Hall, Rm 100
Univ of Maine
Orono, ME 04469-5717
(207) 581-1084
(207) 581-1231 (fax)

MARYLAND

Maryland UAP
The Kennedy Krieger Inst
707 N Broadway
Baltimore, MD 21205-1890
(410) 550-9483
(410) 550-9524 (fax)

The Center for Research on Mental Retardation and Related Aspects of Human Development (R)
Kennedy Krieger Inst
707 N Broadway
Baltimore, MD 21205
(410) 550-9405
(410) 550-9839 (fax)

MASSACHUSETTS

Institute for Community Inclusion
Children's Hospital
300 Longwood Ave
Boston, MA 02115
(617) 355-6509
(617) 355-7940 (fax)

Eunice Shriver Center
200 Trapelo Rd
Waltham, MA 02254
(617) 642-0238
(617) 642-0122 (fax)

Mental Retardation and Developmental Disabilities Research Center (R)
Children's Hospital
300 Longwood Ave
Boston, MA 02115
(617) 735-6386
(617) 730-0228 (fax)

Shriver Mental Retardation Research Center (R)
EK Shriver Center
200 Trapelo Rd
Waltham, MA 02254
(617) 642-0135
(617) 893-4018 (fax)

MICHIGAN

Developmental Disabilities Institute
Wayne State Univ
326 Justice Bldg
6001 Cass Ave
Detroit, MI 48202
(313) 577-2654
(313) 577-3770 (fax)

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MINNESOTA

Institute on Community Integration
102 Pattee Hall
150 Pillsbury Dr SE
Minneapolis, MN 55455
(612) 624-6300
(612) 625-6619 (fax)

MISSISSIPPI

Institute for Disability Studies
Univ of Southern Mississippi
Box 5163
Hattiesburg, MS 39406-5163
(601) 266-5163
(601) 266-5114

MISSOURI

Institute for Human Development
Univ of Missouri, Kansas City
2220 Holmes Street, 3rd Floor
Kansas City, MO 64108
(816) 235-1770
(816) 235-1762 (fax)

MONTANA

Montana University Affiliated Rural Institute on Disabilities Program
52 Corbin Hall
Univ of Montana
Missoula, MT 59812
(406) 243-5467
(406) 243-4730 (fax)

NEBRASKA

Meyer Rehabilitation Institute
Univ of Nebraska Medical Ctr
600 S 44th St
Omaha, NE 68198-5450
(402) 559-6430
(402) 559-5737

NEVADA

University Affiliated Program
Research & Education Planning Ctr
College of Education/MS 278
Univ of Nevada, Reno
Reno, NV 89557-0082
(702) 784-4921
(702) 784-4997 (fax)

NEW HAMPSHIRE

Institute on Disability
Univ of New Hampshire
312 Morrill Hall
Durham, NH 03824-3595
(603) 862-4320
(603) 862-0034 (fax)

NEW JERSEY

UAP of New Jersey
New Jersey's Univ
of the Health Sciences
Robert Wood Johnson
Medical School
PO Box 6810
Piscataway, NJ 08855-6810
(908) 235-4447
(908) 235-5059 (fax)

NEW MEXICO

New Mexico UAP
Univ of New Mexico
School of Medicine
Health Sciences Ctr
Albuquerque, NM 87131
(505) 272-3000
(505) 272-5280 (fax)

NEW YORK

Developmental Disabilities Center
St Luke's-Roosevelt Hospital Ctr
Columbia Univ
1000 Tenth Ave
New York, NY 10019
(212) 523-6230
(212) 523-6241 (fax)

Rose F. Kennedy Center
Albert Einstein College of Medicine
Yeshiva Univ
1410 Pelham Pkwy S
Bronx, NY 10461
(718) 430-2325
(718) 892-2296 (fax)

Strong Center for Developmental Disabilities
Univ of Rochester Medical Center
601 Elmwood Ave
Rochester, NY 14642
(716) 275-2986
(716) 275-3366 (fax)

Westchester Institute for Human Development
325 Cedarwood Hall
Valhalla, New York 10595
(914) 285-8204
(914) 285-1973 (fax)

Rose F Kennedy Center for Research in Mental Retardation & Human Development (R)
Yeshiva Univ
Albert Einstein College of Medicine
1410 Pelham Pkwy S
Bronx, NY 10461
(718) 430-4228
(718) 824-3058 (fax)

NORTH CAROLINA

Clinical Center for the Study of Development & Learning
Univ of North Carolina, Chapel Hill
CB 7255, BSRC
Chapel Hill, NC 27599-7255
(919) 966-5171
(919) 966-2230

Mental Retardation Research Center (R)
Univ of North Carolina, Chapel Hill
Chapel Hill, NC 27599
(919) 966-4250
(919) 966-7532 (fax)

NORTH DAKOTA

North Dakota Center for Disabilities
Minot State Univ
500 University Ave W
Minot, ND 58707
(701) 857-3580
(701) 839-6933 (fax)

NORTHERN MARIANA ISLANDS

Pacific Basin University Affiliated Satellite Program
Northern Mananas College
PO Box 1250
Saipan, MP 96950
(670) 234-5498
(670) 234-0759 (fax)

OHIO

Cincinnati Center for Developmental Disorders
Pavilion Bldg
3333 Burnet Ave
Cincinnati, OH 45229-3039
(513) 559-4688
(513) 559-7361 (fax)

The Nisonger Center
Ohio State Univ
1581 Dodd Dr
Columbus, OH 43210-1205
(614) 292-8365
(614) 292-3727 (fax)

OKLAHOMA

UAP of Oklahoma
Univ of Oklahoma Health
Sciences Ctr
PO Box 26901, ROB 316
Oklahoma City, OK 73190-3042
(405) 271-2688
(405) 271-3087 (fax)

OREGON

University of Oregon UAP
Ctr on Human Development
Univ of Oregon, Eugene
Clinical Services Bldg
Eugene, OR 97403-1265
(503) 346-3591
(503) 346-5639 (fax)

Child Development & Rehabilitation Center
Oregon Health Sciences Univ
PO Box 574
Portland, OR 97207
(503) 494-8364
(503) 494-6868 (fax)

PENNSYLVANIA

Children's Hospital of Pittsburgh
One Children's Pl
3705 Fifth Ave
Pittsburgh, Pa 15213
(412) 692-6523
(412) 692-6660 (fax)

Children's Seashore House
Univ of Pennsylvania
School of Medicine
3405 Civic Ctr Blvd
Philadelphia, PA 19104
(215) 895-3800
(215) 895-3587 (fax)

Institute on Disabilities
Temple Univ
Ritter Hall Annex, Rm 423
13th & Cecil B Moore Ave
Philadelphia, PA 19122
(215) 204-1356
(215) 204-6336 (fax)

Children's Seashore House (R)
Univ of Pennsylvania
School of Medicine
Children's Hospital of Philadelphia
3405 Civic Center Blvd
Philadelphia, PA 19104
(215) 895-3800
(215) 895-3587 (fax)

PUERTO RICO

Developmental Disabilities Institute
Graduate School of Public Health
Medical Science Campus
Univ of Puerto Rico
Box 365067
San Juan, PR 00936-5067
(809) 754-4377
(809) 759-6719 (fax)

RHODE ISLAND

Rhode Island UAP
Inst for Developmental Disabilities
at Rhode Island College
600 Mt Pleasant Ave
Providence, RI 02908
(401) 456-8024
(401) 456-8605 (fax)

SOUTH CAROLINA

South Carolina UAP
Univ of South Carolina
Ctr for Developmental Disabilities
Benson Bldg, 1st Fl
Columbia, SC 29208
(803) 777-4435
(803) 777-6058 (fax)

SOUTH DAKOTA

South Dakota UAP
Univ of South Dakota
School of Medicine
414 E Clark St
Vermillion, SD 57069
(605) 677-5311
(605) 677-6274 (fax)

TENNESSEE

Boling Center for Developmental Disabilities
Univ of Tennessee, Memphis
711 Jefferson Ave
Memphis, TN 38105
(901) 448-6512
(901) 448-7097

JFK Center for Research on Education and Human Development (R)
Box 40, Peabody College
Vanderbilt Univ
Nashville, TN 37203
(615) 322-8242
(615) 322-8236 (fax)

TEXAS

Texas UAP
Univ of Texas, Austin
SZB 306/35300
Austin, TX 78712-1290
(512) 471-7621
(512) 471-7549 (fax)

UTAH

Center for Persons with Disabilities
Utah State Univ
Logan, UT 84322-6800
(801) 797-1981
(801) 797-3944 (fax)

VERMONT

UAP of Vermont
Univ of Vermont
499C Waterman Bldg
Burlington, VT 05405-0160
(802) 656-4031
(802) 656-1357 (fax)

VIRGINIA

Virginia Institute for Developmental Disabilities
Virginia Commonwealth Univ
Box 3020
Richmond, VA 23284-3020
(804) 828-3876
(804) 828-0042 (fax)

VIRGIN ISLANDS

Virgin Islands UAP
Univ of the Virgin Islands
Div of Education
2 John Brewers Bay
St Thomas, VI 00802-9990
(809) 776-9200, ext 1304
809) 755-3351 (fax)

WASHINGTON

Child Development and Mental Retardation Center
Univ of Washington
Mail Stop WJ-10
Seattle, WA 98195
(206) 543-2832
(206) 543-5771 (fax)

Child Development and Mental Retardation Center (R)
Mail Stop WJ-10
Univ of Washington
Seattle, WA 98195
(206) 543-2832
(206) 543-3417 (fax)

WEST VIRGINIA

WV University Affiliated Center for Developmental Disabilities
Research & Office Park
955 Hartman Run Rd
Morgantown, WV 26505
(304) 293-4692
(304) 293-7294 (fax)

WISCONSIN

Waisman Center UAP
Univ of Wisconsin, Madison
1500 Highland Ave
Madison, WI 53705-2280
(608) 263-1656
(608) 263-0529 (fax)

Waisman Center on Mental Retardation and Human Development (R)
Univ of Wisconsin, Madison
1500 Highland Ave
Madison, WI 53705-2280
(608) 263-5940
(608) 263-0529 (fax)

WYOMING

Wyoming Institute for Disabilities
152 A & S Bldg
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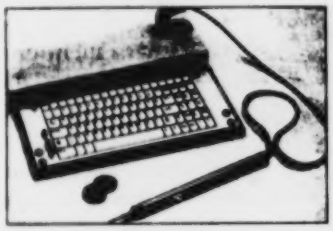

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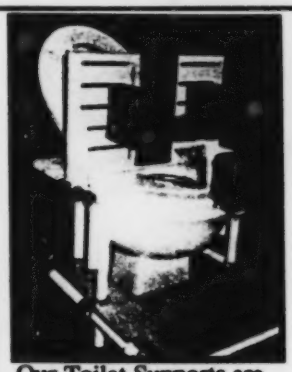

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Circle #27

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Early Intervention Directory

Federal law—the Individuals with Disabilities Education Act (IDEA)—requires all states and territories to provide early intervention and preschool special education for children with disabilities and special health care needs. When available, this directory lists these resources for each state or territory:

- **Central directory (CD) telephone numbers: For families and professionals seeking information about early intervention and other public and private resources for young children, this number is a good place to start. Many toll-free CD numbers are for instate use only. For information on services in other states, call the National Information Clearinghouse for Infants with Disabilities and Life-Threatening Conditions (800/922-9234, ext 201, V/TTY; 803/935-5250, fax).**
- **Coordinators of infant and toddler programs (known as "Part H" programs) serving children from birth to age three.**
- **Chairpersons of Interagency Coordinating Councils ("ICC"). ICCs include representatives of agencies, service providers and families. Their role is to advise and provide assistance on early intervention programs and, in some states, preschool services as well.**
- **Coordinators of preschool special education programs (known as "619" programs) serving children from ages three through eight.**

These listings were provided by the National Early Childhood Technical Assistance Center (NEC*TAS, Frank Porter Graham Child Development Ctr, Univ of North Carolina at Chapel Hill, NationsBank Plz, Ste 500, 137 E Franklin St, Chapel Hill, NC 27514; 919/962-2001, voice; 919/966-4041, TTY; 919/966-7463, fax; nectas@mhs.unc.edu, e-mail) and were current as of November 1995. (Unless otherwise indicated, all telephone numbers are for voice only.)

ALABAMA

CD: (800) 543-3098 (V/TTY)

PART H: OUIDA HOLDER
2129 E South Blvd
Montgomery, AL 36111-0586
(334) 281-8780, ext 395
(334) 613-3494 (fax)

ICC: GLENN HARGER
PO Box 70274
Mobile, AL 36670
(334) 433-9432
(334) 433-8827 (fax)

619: LYNN BOYD
Program for Exceptional Children
State Dept of Education
Gordon Persons Bldg, Rm 3346
50 N Ripley St
Montgomery, AL 36130-2101
(334) 242-8114
(334) 242-9192 (fax)

ALASKA

CD: (800) 478-2221 (V/TTY; AK only)

PART H: SUSAN JONES
Infant Learning Program
State Dept of Health & Social Services
1231 Gambell St
Anchorage, AK 99501-4627
(907) 277-1651
(907) 278-3149 (fax)

ICC: JANELL MEADE
1030 B St
Juneau, AK 99801
(907) 586-5689
(907) 586-8226 (fax)

619: RICHARD SMILEY
Office of Special Services & Support Programs
Alaska Dept of Education
801 W 10th Street, Ste 200
Juneau, AK 99801-1894
(907) 465-8702
(907) 465-3396 (fax)

AMERICAN SAMOA

CD: (684) 633-4929

PART H: JULIA LYONS
Dept of Health
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929/2697
(684) 633-2167 (fax)

ICC: MATT TUNOA
LBJ Tropical Medical Ctr
American Samoa Hospital Authority
Government of American Samoa
Pago Pago, AS 96799
(684) 633-4929
(684) 633-2167 (fax)

619: LINDA AVEGALIO
Special Education
Dept of Education
Box 434
Pago Pago, AS 96799
(684) 633-1323/4789
(684) 633-7707 (fax)

ARIZONA

CD: (800) 232-1676 (V/TTY; AZ only)

PART H: DIANE RENNE
Governor's Council on ICC
Dept of Economic Security
PO Box 6123 801-A-6
Phoenix, AZ 85005
(602) 542-5577
(602) 542-5552 (fax)

ICC: MARY SLAUGHTER
Pilot Parents Partnerships
4750 N Black Canyon Hwy, Ste 101
Phoenix, AZ 85017-3621
(602) 468-3001

GINGER WARD
Southwest Human Development
202 E Earll, #140
Phoenix, AZ 85012
(602) 266-5976

619: LYNN BUSENBARK
Div of Special Education
State Dept of Education
1535 W Jefferson
Phoenix, AZ 85007
(602) 542-3852
(602) 542-5404 (fax)

ARKANSAS

CD: (800) 752-2160

PART H: SHERRY COBB
DD Services, Dept of Human Services
Donaghey Plaza N
PO Box 1437, Slot 2520
7th & Main Sts
Little Rock, AR 72203-1437
(501) 682-8676
(501) 682-8890 (fax)

ICC: DANNY GREEN
2107 Houston
El Dorado, AR 71730
(501) 864-6435

VENITA LOVELACE-CHANDLER
45 Laver Cir
Little Rock, AR 72209
(501) 450-3611
(501) 450-5503 (fax)

619: SANDRA REIFEISS
Preschool Programs
Special Education Section
State Dept of Education
#4 Capitol Mall, Rm 105-C
Little Rock, AR 72201
(501) 682-4222
(501) 682-4313 (fax)

CALIFORNIA

CD: (800) 515-2229

PART H: BETH GOULD
Early Intervention Program
Dept of Developmental Services
1600 9th St, Rm 310
Sacramento, CA 95814
(916) 654-2773
(916) 654-3255 (fax)

ICC: RAYMOND M PETERSON
San Diego-Imperial Cnty Developmental Services
4355 Ruffin Rd, Ste 206
San Diego, CA 92123-1648
(619) 576-2932
(619) 576-2873 (fax)

619: CONNIE BORNE
Special Education Div
State Dept of Education
PO Box 944272
Sacramento, CA 94244-2720
(916) 327-3696
(916) 327-3516 (fax)

COLORADO

CD: (800) 288-3444 (CO only)

PART H: DIANE TURNER
Special Education Div
State Dept of Education
201 E Colfax, Rm 301
Denver, CO 80203
(303) 866-6667
(303) 866-6662 (fax)

ICC: JERRI MILLER
2810 Shady Dr
Colorado Springs, CO 80918
(719) 590-7086

BARBARA STUTSMAN
The Disability Connection
PO Box 270714
Ft Collins, CO 80527
(303) 229-0224
(303) 339-0242 (fax)

619: JANE L AMUNDSON
Special Education Div
State Dept of Education
210 E Colfax, Rm 300
Denver, CO 80203-1799
(303) 866-6712
(303) 866-6662 (fax)

CONNECTICUT

CD: (800) 505-7000 (V/TTY; CT only)

PART H: KAY HALVERSON
Early Childhood Unit
State Dept of Education
25 Industrial Pk Rd
Middletown, CT 06457
(203) 638-4208
(203) 638-4218 (fax)

ICC: DEBORAH HAFNER
Univ of Connecticut Health Ctr
309 Farmington Ave
Farm Hollow, Ste A-200
Farmington, CT 06032
(203) 679-4637
(203) 679-1368 (fax)

619: MARIA SYNODI
State Dept of Education
25 Industrial Pk Rd
Middletown, CT 06455
(203) 638-4211
(203) 638-4218 (fax)

DELAWARE

CD: (302) 577-4643

PART H: NANCY WILSON
Management Services Div
Health & Social Services
1901 N Dupont Hwy, Rm 231
Newcastle, DE 19720
(302) 739-4604
(302) 739-4654 (fax)

ICC: JERRY ICENOGLE
Blue Cross Blue Shield of Delaware
1 Brandywine Gateway
Wilmington, DE 19899
(302) 421-3452
(302) 577-4083 (fax)

619: MARTHA TOOMEY
Dept of Public Instruction
Townsend Bldg
PO Box 1402
Dover, DE 19703
(302) 739-4667
(302) 739-2388 (fax)

DISTRICT OF COLUMBIA

CD: (202) 727-8300

PART H: JOAN CHRISTOPHER
DC-EIP Services
609 H St NW, 5th Fl
Washington, DC 20002
(202) 727-5930
(202) 727-5971 (fax)

ICC: TAWANA TAYLOR
Georgetown Univ Child Dev Ctr
3307 M St NW
Washington, DC 20007
(202) 687-8635
(202) 687-8899 (fax)

619: B GARNET PINKNEY
Office of Special Education
Goding School
10th & F Sts NE
Washington, DC 20002
(202) 724-4800
(202) 724-2397 (fax)

FLORIDA

CD: (800) 654-4440 (FL only)

PART H: FRAN WILBER
Children's Medical Services
1317 Winewood Blvd, Bldg 8
Tallahassee, FL 32399-0700
(904) 488-6005
(904) 921-5241 (fax)

ICC: ROBERT GRIGGS
Florida Easter Seal Society
1010 Executive Ctr Dr, Ste 231
Orlando, FL 32803
(407) 896-7881
(407) 896-8422 (fax)

619: NANCY D THOMAS
Pre-Kindergarten EI Programs
Office of EI & School Readiness
Florida Dept of Education
325 W Gaines St, Ste 754
Tallahassee, FL 32399-0400
(904) 488-6830
(904) 487-0946 (fax)

GEORGIA

CD: (800) 229-2038 (V/TTY; GA only)

PART H: WENDY SANDERS
Div of Public Health
Dept of Human Resources
2 Peachtree St, 7th Fl
Atlanta, GA 30303
(404) 657-2727
(404) 657-2763 (fax)

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ICC: TISH SEAY
Georgia College
Dept of Special Education
CBX 072
Milledgeville, GA 31061
(912) 453-4577
(912) 453-6582 (fax)

619: BRENDA BACHECHI
Dept for Exceptional Students
Georgia Dept of Education
1970 Twin Towers E
Atlanta, GA 30334-5010
(404) 657-9955
(404) 651-6457 (fax)

GUAM

CD: (671) 475-0549 or 0554

PART H/619: VINCE LEON GUERRERO
Special Education Div
Dept of Education
PO Box DE
Agana, GU 96910
(671) 647-4400
(671) 646-8052 (fax)

ICC: MAMIE C BALAJADIA
Dept of Mental Health & Substance Abuse
790 Gov Carlos Camacho Rd
Tamuning, GU 96911
(671) 647-5440
(671) 649-6948 (fax)

HAWAII

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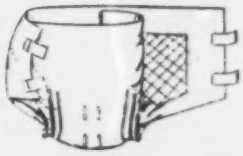

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The listings in this directory were provided by the National Association of State Directors of Special Education (NASDSE, 1800 Diagonal Rd, Alexandria, VA 22314; 703/519-3800, voice; 703/519-7008, TTY; 703/519-3808, fax) and were current as of November 1995.

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Special Education
Dept of Education
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Arizona Dept of Education
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(602) 542-5404 (fax)

Ronald Autry, 12, loves to go frog hunting. He and his grandmother, Wineba Pederson, catch frogs, keep them in a pond in the backyard for the summer, then turn them loose in the fall. Ron, who has autism, also loves other animals, especially his dog and cat. Ron lives in Des Moines, Iowa, with his parents, James Autry and Sally Pederson.

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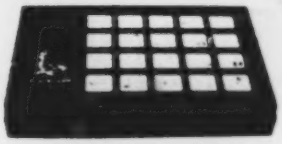

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- Metabolic & Degenerative Diseases
- Learning Problems and Disabilities
- Mental Retardation
- Head Injury
- Birth Defects
- Cerebral Palsy
- Feeding Disorders
- Behavior Problems
- Down Syndrome
- Other Special Needs

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Baltimore, MD 21205

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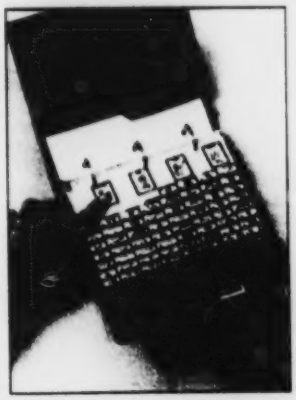

- 546 pictures for direct selection with upper-case captions. Serves as a copy-source for reading skills development and cognitive rehabilitation.
- provides single-word voice output (no text-to-speech)
- keyboard has dictionary, thesaurus and spell-correction functions

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1 (800) 724-7301

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Federal & Federally-Funded Information Resources

The federal government supports many clearinghouses, information centers and institutes that focus on specific topics. In addition to publishing and distributing extensive free material on disability-related subjects, many of the clearinghouses, centers and institutes also provide referrals to local resources. Staff and funding varies. Because of small staff, several clearinghouses have asked that their phone numbers not be listed; they are happy to respond to written requests for information.

For more information on federal and federally-funded information resources, contact:

- **NICHCY** (National Information Center for Children and Youth with Disabilities), PO Box 1492, Washington, DC 20013-1492, (800) 695-0285 (V/TTY), (202) 884-8741 (fax).
- **NARIC** (National Rehabilitation Information Center), 8455 Colesville Rd, Ste 935, Silver Spring, MD 20910, (800) 346-2742, (301) 588-9284 (V/TTY), (301) 587-1967 (fax).
- **NHIC** (National Health Information Center), P.O. Box 1133, Washington, DC 20013-1133, (800) 336-4797 (voice), (301) 984-4256 (fax).

GENERAL

Agency for Health Care Policy and Research Publications Clearinghouse
PO Box 8547
Silver Spring, MD 20907-8547
(800) 358-9295 (voice)
(410) 381-3150 (voice)

Clearinghouse on Disability Information
Office of Special Education and Rehabilitation Services
US Dept of Education
330 C St, SW
Switzer Bldg, Rm 3132
Washington, DC 20202-2524
(202) 205-8241 (V/TTY)
(202) 205-9252 (fax)

National Center for Education in Maternal and Child Health
2000 15th St N, Ste 701
Arlington, VA 22201-2617
(703) 524-7802 (voice)
(703) 524-9335 (fax)
ncemch01@gumedlib.dml.georgetown.edu

National Center for Health Statistics
6525 Belcrest Rd
Hyattsville, MD 20782
(301) 436-8500 (voice)
(301) 436-3797 (fax)
nchsquery@nch10a.em.cdc.gov

National Health Information Center (NHIC)
PO Box 1133
Washington, DC 20013-1133
(800) 336-4797 (voice)
(301) 565-4167 (voice)
(301) 984-4256 (fax)
nhicinfo@health.org

National Information Center for Children and Youth with Disabilities (NICHCY)
PO Box 1492
Washington, DC 20013-1492
(800) 695-0285 (V/TTY)
(202) 884-8200 (V/TTY)
(202) 884-8441 (fax)
nichcy@aed.org

National Institute of Child Health and Human Development
PO Box 29111
Washington, DC 20040
(301) 496-5133 (voice)
(301) 496-7101 (fax)

National Maternal and Child Health Clearinghouse
2070 Chain Bridge Rd, Ste 450
Vienna, VA 22182
(703) 821-8955, ext 254, 265 or 317 (voice)
(703) 821-2098 (fax)

National Rehabilitation Information Center (NARIC)
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910
(800) 346-2742 (voice)
(301) 588-9284 (voice)
(301) 495-5626 (TTY)
(301) 587-1967 (fax)

Office of Minority Health Resource Center
PO Box 37337
Washington, DC 20013-7337
(800) 444-6472 (voice)
(301) 589-0951 (TTY)
(301) 589-0884 (fax)

AIDS

Centers for Disease Control and Prevention National AIDS Clearinghouse
PO Box 6003
Rockville, MD 20849-6003
(800) 458-5231 (voice)
(800) 342-2437 (English hotline)
(800) 344-7432 (Spanish hotline)
(800) 243-7012 (TTY)
(301) 738-6616 (fax)
(301) 217-0023 (international line)

ALLERGY & INFECTIOUS DISEASES

National Institute of Allergy and Infectious Diseases
Office of Communication
Bldg 31, Rm 7A50
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5717 (voice)
(301) 402-0120 (fax)

ASSISTIVE TECHNOLOGY & REHABILITATION

ABLEDATA
8455 Colesville Rd, Ste 935
Silver Spring, MD 20910-3319
(800) 227-0216 (voice)
(301) 588-9284 (voice)
(301) 495-5626 (TTY)
(301) 587-1967 (fax)

CANCER

Cancer Information Service
National Cancer Inst
Bldg 31, Rm 10A16
Bethesda, MD 20892
(800) 422-6237 (voice)
(800) 332-8615 (TTY)
(301) 496-5583 (voice)

DIABETES

National Diabetes Information Clearinghouse
1 Information Wy
Bethesda, MD 20892-3560

DIGESTIVE DISEASES

National Digestive Diseases Information Clearinghouse
2 Information Wy
Bethesda, MD 20892-3570

EDUCATION

ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children
1920 Association Dr
Reston, VA 22091-1589
(800) 328-0272 (voice)
(703) 264-9474 (voice)
(703) 264-9449 (TTY)
(703) 264-9494 (fax)
ericec@inet.ed.gov

National Clearinghouse on Postsecondary Education for Individuals with Disabilities
HEATH Resource Ctr
1 Dupont Cir NW, Ste 800
Washington, DC 20036-1193
(800) 544-3284 (V/TTY)
(202) 939-9320 (V/TTY)
(202) 833-47560 (fax)
heath@ace.nche.edu

HEARING IMPAIRMENTS

National Information Center on Deafness
Gallaudet Univ
800 Florida Ave NE
Washington, DC 20002-3695
(202) 651-5051 (voice)
(202) 651-5052 (TTY)
(202) 651-5054 (fax)
nicd@gallux.gallaudet.edu

National Institute on Deafness and Other Communication Disorders Information Clearinghouse
1 Communication Ave
Bethesda, MD 20892-3456
(800) 241-1044 (voice)
(800) 241-1055 (TTY)
(301) 907-8830 (fax)
nidcd@aene.com

HEART, LUNG & BLOOD DISORDERS

National Heart, Lung, and Blood Institute Information Center
PO Box 30105
Bethesda, MD 20824-0105
nhlbiic@dgsys.com

HOUSING

Housing and Urban Development User
PO Box 6091
Rockville, MD 20849
(800) 245-2691 (voice)
(301) 251-5154 (voice)
(800) 483-2209 (TTY)
(301) 251-5767 (fax)
huduser@aspensys.com

KIDNEY & UROLOGIC DISEASES

National Kidney and Urologic Diseases Information Clearinghouse
3 Information Wy
Bethesda, MD 20892-3580
(301) 654-4415 (voice)
(301) 907-8906 (fax)

MENTAL HEALTH

National Clearinghouse on Family Support and Children's Mental Health
Portland State Univ
PO Box 751
Portland, OR 97207-0751
(800) 628-1696 (voice)
(503) 725-4040 (voice)
(503) 725-4165 (TTY)
(503) 725-4180 (fax)

MUSCULOSKELETAL & SKIN DISEASES

National Arthritis and Musculoskeletal and Skin Diseases Information Clearinghouse
1 AMS Cir
Bethesda, MD 20892-3675
(301) 495-4484 (voice)
(301) 565-2966 (TTY)
(301) 587-4352 (fax)

NEUROLOGICAL DISORDERS

National Institute of Neurological Disorders & Stroke
PO Box 5801
Bethesda, MD 20824
(800) 352-9424 (voice)
(301) 496-5751 (voice)
(301) 402-2186 (fax)

ORAL HEALTH

National Oral Health Information Clearinghouse
1 NOHIC Wy
Bethesda, MD 20892
(301) 402-7364 (voice)
(301) 907-8830 (fax)
nidr@aene.com

PRIMARY CARE

National Clearinghouse for Primary Care Information
2070 Chain Bridge Rd, Ste 450
Vienna, VA 22182
(703) 821-8955, ext 248 (voice)
(703) 821-2098 (fax)

SUBSTANCE ABUSE

The Resource Center on Substance Abuse
1819 L St NW, Ste 300
Washington, DC 20036
(202) 628-8080 (voice)
(202) 638-5862 (TTY)
(202) 628-3812 (fax)

VISUAL IMPAIRMENTS

National Eye Institute
Bldg 31, Rm 6A32
31 Center Dr, MSC 2510
Bethesda, MD 20892-2510
(301) 496-5248 (voice)
(301) 402-1065 (fax)
2020@b31.nei.nih.gov

Who says chivalry is dead? **Michael Joseph Marek**, 8, holds his one-year-old sister, **Lauren**, tightly as they take a ride down the slide. The two are great friends—their favorite activity is dancing together to Janet Jackson's music. Mike, who has cerebral palsy and lives in Park Ridge, Illinois, also enjoys reading and playing basketball.

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OTHER FEDERAL RESOURCES

These federal resources can provide information on programs, services and related laws and regulations.

Administration on Developmental Disabilities
US Dept of Health and Human Services
HHH Bldg, Rm 329D
200 Independence Ave SW
Washington, DC 20201
(202) 690-6590 (voice)
(202) 690-6415 (TTY)
(202) 690-6904 (fax)
◆ *Develops and administers programs protecting rights and promoting independence, productivity and inclusion; funds state grants, Protection and Advocacy programs, University Affiliated Programs and other national projects.*

Department of the Interior
National Park Service
PO Box 37127
Washington, DC 20013-7127
(202) 208-4747 (voice)
(202) 219-0910 (fax)
◆ *Provides maps of national parks with general accessibility. Some parks offer free passes for people with disabilities. Contact individual parks for more information.*

Division of Birth Defects and Developmental Disabilities
National Center for Environmental Health
Centers for Disease Control and Prevention
4770 Buford Hwy NE
Mailstop F-34
Atlanta, GA 30341-3724
(770) 488-7150 (voice)
(770) 488-7156 (fax)
◆ *Provides assistance to health departments and community organizations to implement prevention programs.*

Indian Health Service
Mental Health/Social Service Programs Branch
5300 Homestead Rd NE
Albequerque, NM 87110
(505) 837-4245 (V/TTY)
(505) 837-4257(fax)
◆ *Provides mental health services to Native American children with special needs and their families.*

Job Accommodation Network
West Virginia University
Morgantown, WV 26506-6080
(800) 232-9675 (V/TTY)
(800) 526-7234 (V/TTY)
(800) 526-2262 (V/TTY, Canada)
(304) 293-5407 (fax)
✉ jan@jan.icdi.wvu.edu
◆ *Provides information about job accommodations, the employability of people with functional limitations and the Americans with Disabilities Act (ADA).*

National Council on Disability
1331 F St NW, Ste 1050
Washington, DC 20004-1107
(202) 272-2004 (voice)
(202) 272-2074 (TTY)
(202) 272-2022 (fax)
◆ *An independent federal agency working with the President and Congress to increase the inclusion, independence and empowerment of all Americans with disabilities.*

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor St NW
Washington, DC 20542
(202) 707-5100 (voice)
(202) 707-0744 (TTY)
(202) 707-0712 (fax)
◆ *Provides Braille and recorded books and magazines on free loan to anyone who cannot read standard print because of visual or physical disabilities.*

Office of Fair Housing and Equal Opportunity
Department of Housing and Urban Development
820 1st St NE, Ste 420
Washington, DC 20002
(202) 275-0848 (voice)
(202) 275-0772 (TTY)
(202) 275-0779 (fax)
◆ *Provides information and handles complaints about discrimination in housing.*

Office of Special Education and Rehabilitative Services (OSERS)
US Dept of Education
Switzer Bldg
330 C St SW
Washington, DC 20202
(202) 205-8723 (voice)
(202) 205-8241 (TTY)
(202) 205-9252 (fax)
◆ *Supports educational programs for children with special needs, the rehabilitation of people with disabilities and research to improve the lives of people with disabilities.*

President's Committee on Employment of People with Disabilities
1331 F St NW, 3rd Fl
Washington, DC 20004
(202) 376-6200 (voice)
(202) 376-6205 (TTY)
(202) 376-6219 (fax)
◆ *Produces public information campaigns, and publishes and distributes free material on employment of people with disabilities, independent living, the Rehabilitation Act and job accommodation and placement.*

President's Committee on Mental Retardation
Wilbur J Cohen Bldg, Rm 5325
330 Independence Ave SW
Washington, DC 20201
(202) 619-0634 (voice)
(202) 205-9519 (fax)
◆ *Advises the President and the Secretary of Health and Human Services on providing services for people with mental retardation and on ways to prevent this disability. Publishes annual reports, bibliographies, conference reports and information on such topics as the legal rights of people with mental retardation.*

Senate Subcommittee on Disability Policy
113 Hart Senate Office Bldg
Washington, DC 20510
(202) 224-6265 (voice)
(202) 224-3457 (TTY)
(202) 228-2923 (fax)
◆ *Has legislative jurisdiction over the Americans with Disabilities Act (ADA), Individuals with Disabilities Education Act (IDEA), Rehabilitation Act, Developmental Disabilities Act and Technology-Related Assistance for Individuals with Disabilities Act.*

Social Security Administration
6401 Security Blvd
Baltimore, MD 21235
(800) 772-1213 (voice hotline)
(800) 325-0778 (TTY hotline)
(410) 965-7700 (voice)
(410) 965-0695 (fax)
◆ *Provides information about the Social Security and Supplemental Security Income (SSI) programs, disability benefits and Medicare.*

CANADIAN RESOURCES

The following Canadian resources can provide information on disability-related topics and referrals to local resources. In addition to the federally-funded Canadian Clearinghouse on Disability Issues, most provincial governments fund similar information resources for their citizens. For those provinces that do not provide this type of government-funded center, we have listed the non-governmental organization that serves the same function. Non-governmental organizations are identified by an asterisk (*) following the program name.

NATIONAL CLEARINGHOUSE

Canadian Clearinghouse on Disability Issues
Human Resources Development Canada
25 Eddy St, Ste 100
Hull, PQ K1A 0M5
(800) 665-9017 (voice; CAN only)
(800) 561-9706 (TTY; CAN only)
(819) 953-1194
(819) 953-4797 (fax)
994-7514 (in the Ottawa Area)

PROVINCIAL RESOURCES

ALBERTA

Premier's Council on the Status of Persons With Disabilities
#250, 11044-82 Ave
Edmonton, AB T6G 0T2
(800) 272-8841 (V/TTY; AB only)
(403) 422-1095 (V/TTY)
(403) 422-9691 (fax)

BRITISH COLUMBIA

Office for Disability Issues
#100, 333 Quebec St
Victoria, BC V8V 1X4
(800) 663-7867 (voice; BC only)
(800) 661-6773 (TTY; BC only)
(604) 387-3813 (voice)
(604) 387-3555 (TTY)
(604) 387-3114 (fax)

MANITOBA

Manitoba League of Persons With Disabilities*
#200, 294 Portage Ave
Winnepeg, MB R3C 0B9
(204) 943-6099 (V/TTY)
(204) 942-3146 (fax)

NEW BRUNSWICK

Premier's Council on the Status of Disabled Persons
#648, 440 King St
Fredericton, NB E3B 5H8
(800) 442-4412 (V/TTY; NB only)
(506) 452-1112 (V/TTY)
(506) 450-2747 (fax)

NEWFOUNDLAND

Family and Rehabilitative Services
Dept of Social Services
3rd Fl, Confederation Bldg
St. John's, NF A1B 4J6
(709) 729-2436 (voice)
(709) 729-0583 (fax)
✉ dgallant@doss.gov.nf.ca

NORTHWEST TERRITORIES

NWT Council for Disabled Persons*
PO Box 1387
Yellowknife, NT X1A 2P1
(403) 873-8230 (voice)
(403) 920-2674 (TTY)
(403) 873-4124 (fax)

NOVA SCOTIA

Disabled Persons Commission
#203, 2695 Dutch Village Rd
Halifax, NS B3L 4T9
(800) 565-8280 (V/TTY; NS only)
902) 424-8280 (voice)
(902) 424-2667 (TTY)
✉ dpcomm@fox.nstn.ca

PRINCE EDWARD ISLAND

PEI Coucil of the Disabled*
PO Box 2128
Charlottetown, PE C1A 7N7
(800) 653-9555 (V/TTY; PEI only)
(902) 892-9149 (V/TTY)
(902) 566-1919 (fax)
✉ peicodi@mail.peinet.pe.ca

QUEBEC

Office des Personnes Handicapees du Quebec
309 Rue Brock
Drummondville, PQ J2B 1C5
(800) 567-1465 (voice; PQ only)
(800) 567-1477 (TTY; PQ only)
(819) 475-8585 (voice)
(819) 475-8753 (fax)

SASKATCHEWAN

Disabilities Directorate
Saskatchewan Labour
3rd Fl, 1870 Albert St
Regina, SK S4P 3V7
(306) 787-5101 (voice)
(306) 787-9105 (TTY)
(306) 787-4038 (fax)

YUKON TERRITORY

Health and Social Services
Community Support Services
PO Box 2703
Whitehorse, YT Y1A 2C6
(403) 667-5774 (V/TTY)
(403) 667-6078 (fax)

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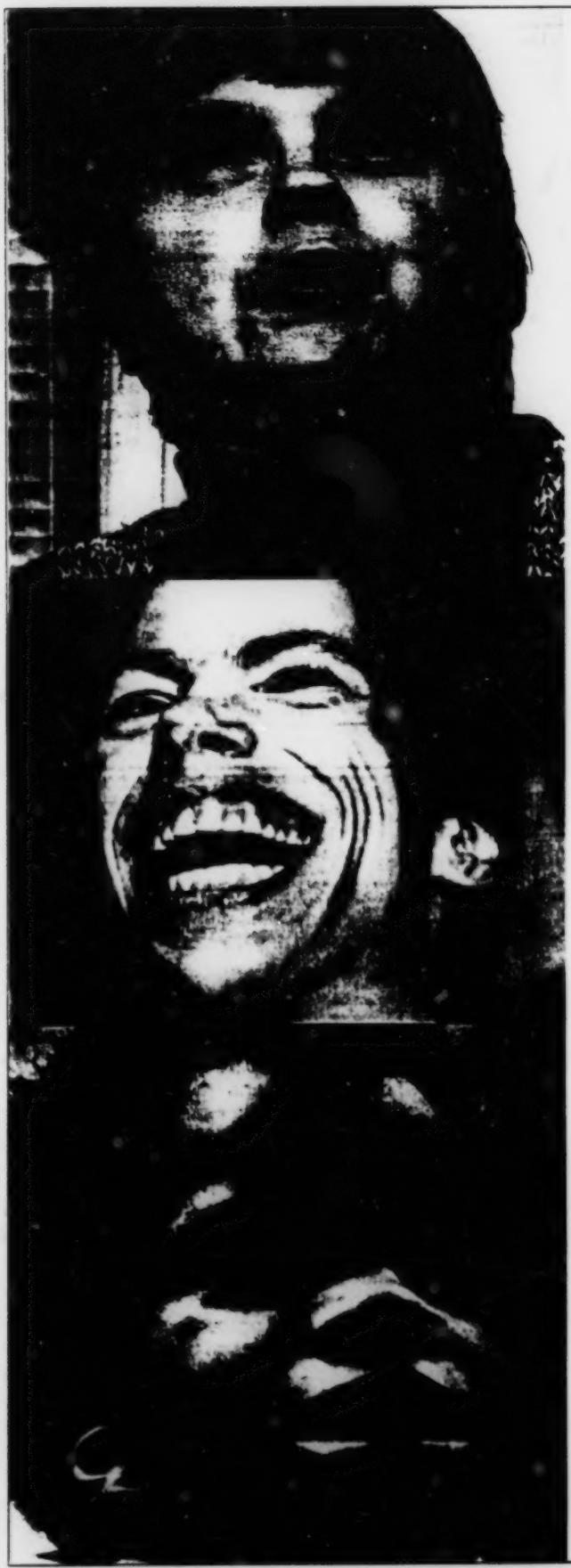

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120 Holcomb Street • Hartford, CT 06112 • 860/242-2274

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Centerville, Ohio 45459
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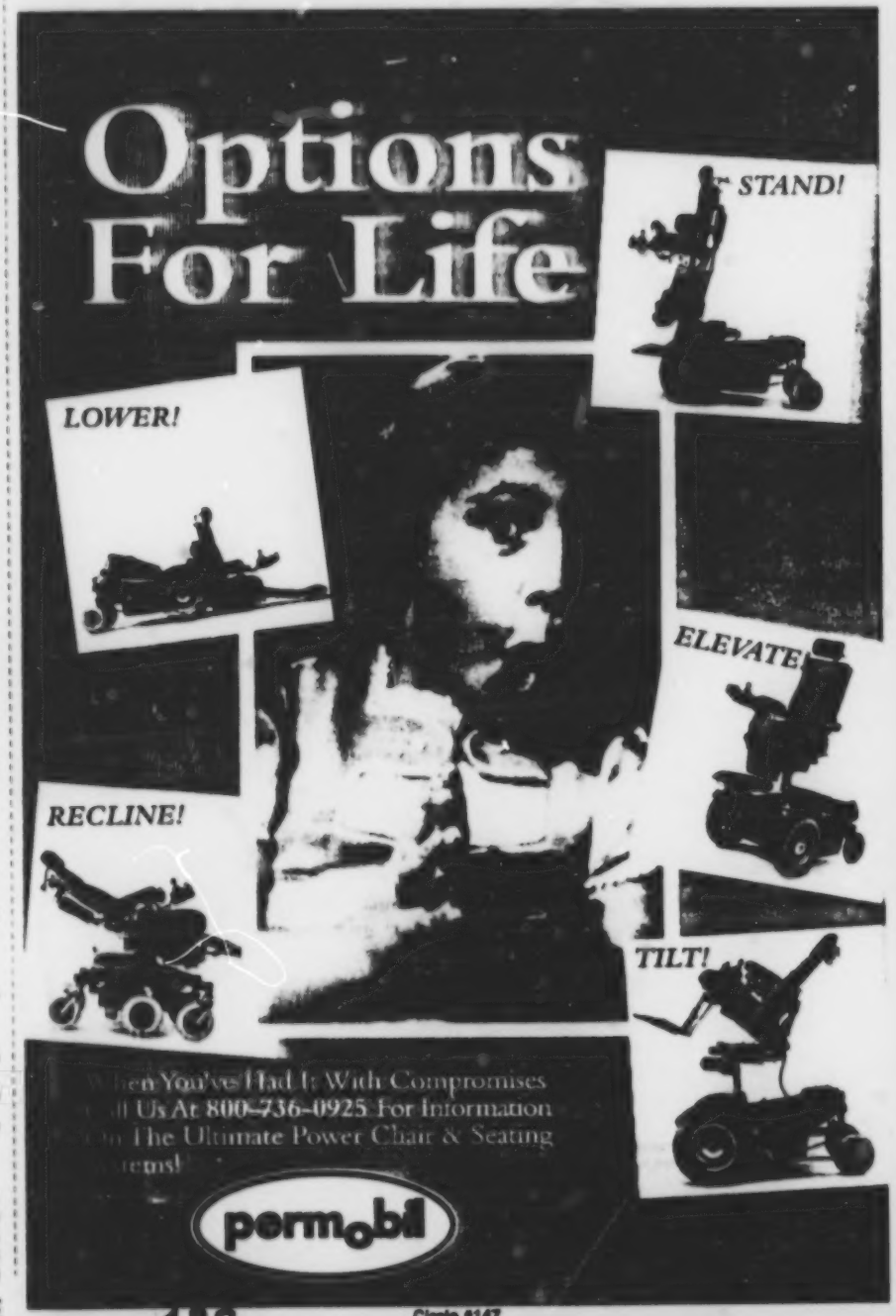

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Menstruation (sanitary pads) and Cerebral Palsy	Apr	
Mental Retardation, biting problem in	Nov	
Metabolic Bone Disorders	Mar	
Microcephaly/Encephalocele	Feb	Apr
Muscular Dystrophy, Congenital	Oct	
Near-drowning, resulting in Anoxic Brain Damage	Mar	
Omphalocele, of Liver	Apr	Aug
Opitz Syndrome, Turner Syndrome, G-Tube Problems	Aug	
Partial Trisomy 15, Chromosome Ten Partial Monosomy	Mar	
Partial Trisomy 15	Aug	
PDD (Pervasive Developmental Disorder) and feelings of isolation	Jun	
Peters Anomaly and dental problems (fused teeth)	Jul	
Poliodystrophy, Progressive Infantile	Jun	
Recreation, Therapeutic	Dec '94	Jun
Residential Care	Jul	Sep
Rh Incompatibility and Cerebral Palsy	Oct	
Sanitary Pads used in menstruation and Cerebral Palsy	Apr	
Screaming in public	Dec '94	Mar, May
Scoliosis and Failure to Thrive	Dec	
Self-stimulation and smearing	Jul	Oct
Seizures and Stroke	Sep	
Seizures, dealing with	May	Jul, Aug
Seizures, in EME (Early Myoclonic Encephalopathy)	Oct '93	Jun
Self-Catheterization	Oct '94	Feb
Sibling, Adult, caring for	Dec	
Side-effects of Anticonvulsants	Dec	Dec
Smearing and self-stimulation	Jul	Oct
Speech, Developmental Apraxia of (DAS)	Jul	
Speech Difficulties and emergencies	Nov	
Spina Bifida	Oct '94	Feb
Spina Bifida and Autism	Apr	
Spina Bifida, Leg Braces and ripped clothing	Dec	
Spasms, Infantile, from stroke	Sep	
Step-families	Nov '94	Feb
Stressful car rides and hypotonia, central (unspecified)	Apr	Apr, Jul
Stockinettes for Leg Braces, acquiring	May	Nov
Stroke and Seizures	Sep	
Stroke, resulting in infantile spasms	Sep	
Swinging Objects and Down Syndrome	Apr	Aug, Nov
Telling a child about her disease; Alpha-Mannosidosis	May	
Tibia and Fibula, bowing of	Aug	
Toilet Training, equipment	Oct	
Turner Syndrome, Opitz Syndrome, G-Tube problems	Aug	
Undiagnosed	Jun	
Undiagnosed	Sep	
Undiagnosed	Oct	
Undiagnosed, cerebellar atrophy	Sep	
Undiagnosed (Duchenne Muscular Dystrophy?)	Mar	May
Undiagnosed (Ehlers-Danlos Syndrome?)	Mar	May
Undiagnosed, two children	Aug	
Van conversions and cerebral palsy	Apr	
Vein of Galen, AVM (arteriovenous malformation) of	Feb	
Water beds or other mattresses in cerebral palsy	Jul	Oct

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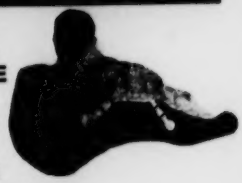

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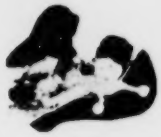

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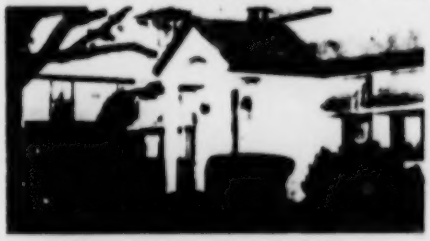

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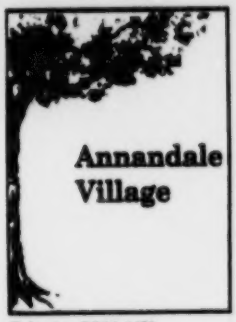

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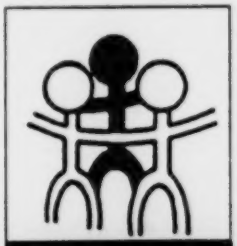

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Product & Service Directory

The listings in this directory were purchased by the listed companies or organizations. Representatives from each company selected the category or categories under which they are listed.

ADA INFO, CAREER PLANNING

Devereux
19 S Waterloo Rd
Devon, PA 19333
(610) 964-3030 Fax (610) 971-4600
See our ad on page 75
Circle #199

AUGMENTATIVE COMMUNICATIONS EQUIPMENT

Ability Research
PO Box 1721
Minnetonka, MN 55345
(612) 939-0121 Fax: (612) 890-8393
Action Voice-2™ digital voice messages prompted Auditory Scanning; 2 switch closures/keypad/multiple switch/scanning LightBeam™, LightSwitch™.

Adaptive Switch Labs
PO Box 202756
Austin, TX 78720-2756
(800) 626-8698 Fax: (800) 393-4408
See our ad on page 88
Circle #126

Communication Devices, Inc
2433 Government Wy, Ste A
Coeur d'Alene, ID 83814
(800) 60-HOLLY Fax: (208) 765-1529
See our ad on page 4
Circle #143

Crestwood Company
6625 N Sidney Pl
Milwaukee, WI 53209
(414) 352-5678 Fax: (414) 352-5679

DC & D, Inc
42 Skinner Rd
E Windsor, CT 06016
(860) 623-7364 Fax: (860) 623-2941
See our ad on page 95
Circle #92

GMR LABS
1030 E El Camino Real
#308 Sunnyvale, CA 94087-3759
(800) 234-8288 Fax: (408) 985-7200
See our ad on page 20
Circle #4
Vocal Assistant™ line of portable voice output comm. products. Messages can be recorded in any voice or language. Auditory & visual scanning.

Gus Communications, inc
1006 Lonetree Ct
Bellingham, WA 98226
(360) 715-8580 Fax: (360) 715-9633
See our ad on page 56
Circle #103
The Gus! Multimedia Speech System for Windows converts ANY Windows type computer into a dynamic display speech output device.

Innocomp
26210 Emery Rd
Warrenville, OH 44128
(216) 464-3636 Fax: (216) 464-3638
See our ad on page 80
Circle #245
Portable text-to-speech systems.Includes say-it-all, say-it-simple plus/or scan-it-all. Available with DEC talk speech synthesizer.

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #29

L. C. Technologies
9455 Silver King Ct
Fairfax, VA 22031
(703) 385-7133 Fax: (703) 385-7137
See our ad on page 76
Circle #26

Passy-Muir Trach/Vent Speaking Valves
4512 Campus Dr. #273
Irvine, CA 92715
(800) 634-5397 Fax: (714) 833-8299

Rhamdec, inc
476 Ellis St
Mt View, CA 94043
(800) 4-MYDESC Fax: (415) 965-0705
See our ad on page 125
Circle #5

See A Need
8864 Kalmar Dr
Colorado Springs, CO 80920
(719) 282-0141
RedLite Optical Pointer shines a red target on an alphabet or picture board $90 + $6 S&H. 30 day money back guarantee.

Sentient Systems Technology, inc
2100 Wharton St, Ste 630
Pittsburgh, PA 15203
(800) 344-1778 Fax: (412) 381-5241
See our ad on page 84
Circle #111
Sentient Systems offers advanced communication devices & software for preschoolers, students & adults who have difficulty speaking.

Techno Genesis, Inc
PO Box 11976
Prescott, AZ 86304-1976
(520) 778-5611 Fax: (520) 778-2423
High Tech/Low Cost book & video show how to build AT devices plus 12 strategies to save $$$ on AT. Expanded 1996 Ed. Free Brochure.

Tiger Communication Systems, Inc
328 Main St E, Ste 514
Rochester, NY 14604
(800) 724-7301 Fax: (716) 454-3631
See our ad on page 110
Circle #64

Touch Turner Company
443 View Ridge Dr
Everett, WA 98203
(206) 252-1541 Fax: (206) 259-4390
Pages turned in either direction, operated by flashlight batteries, sensitive switches, hand, breath, large target, etc. Free brochure.

Toys For Special Children/Enabling Dvcs
385 Warburton Ave
Hastings, NY 10706
(914) 478-0960 Fax: (914) 478-7030
See our ad on page 106
Circle #151

Wayne County R.E.S.A. - Adamlab
33500 Van Born Rd
Wayne, MI 48184-2497
(313) 467-1415 Fax: (313) 326-2610
See our ad on page 109
Circle #123
Low cost. Blackhawk, $650, digital speech total of 64 messages on 4 levels. Hawk, $250, digital speech, total of 9 messages on 1 level. Very easy to program, free catlg.

AUGMENTATIVE EVALUATION

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1984 Fax: (216) 263-4829

Sundance Technologies & Training Ctr
6721-D Academy Rd. NE
Albuquerque, NM 87109
(505) 858-0142 Fax: (505) 858-0342

BATHROOM EQUIPMENT

Adaptive Design Shop
12847 Pt Pleasant Dr
Fairfax, VA 22033
(703) 631-1585
See our ad on page 100
Circle #27

Barrier Free Lifts®, Inc
9230 Prince William St
Manassas, VA 22110
(800) 582-8732 Fax: (703) 361-7861
See our ad on page 80
Circle #36

Beatrice M. Brantman, inc
207 E Westminster
Lake Forest, IL 60045
(800) 232-7987 Fax: (708) 615-8894
See our ad on page 110
Circle #234
Completely portable transfer systems made of space age materials, which provide for a safe, controlled lateral slide-NO MORE LIFTING!

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612 Fax: (310) 305-1718
See our ad on page 8
Circle #69

Fiberglass Access
PO Box 501176
Malabar, FL 32950
(407) 729-1426 Fax: (407) 729-1426

Linido USA
1090 McCallie Ave
Chattanooga, TN 37404
(800) 698-4504 Fax: (423) 629-8810
See our ad on page 140
Circle #58

Lubidet USA, Inc
1980 S Quebec St. Ste 4
Denver, CO 80231-3234
(800) 582-4338 Fax: (303) 368-0812
See our ad on page 88
Circle #113

National Access Products
540 W Boston Post Rd
Mamaroneck, NY 10543-3437
(800) 285-7814 Fax: (800) 285-2525
See our ad on page 91
Circle #10

Rifton
PO Box 901
Rifton, NY 12471
(800) 374-3866 Fax: (800) 336-5948
See our ad on page 57
Circle #45

Snug Seat, Inc
PO Box 1739
Matthews, NC 28106
(800) 336-7684 Fax: (704) 847-9577
See our ad on page 22
Circle #211

Tumble Forms
145 Tower Dr
Burr Ridge, IL 60521
(800) 323-5547 Fax: (800) 547-4333
See our ad on the back cover
Circle #182

BEDDING

Hard Manufacturing
230 Grider St
Buffalo, NY 14215
(800) USE-HARD Fax: (716) 896-2579
See our ad on page 16
Circle #60
Our Age Appropriate beds and cribs accommodate your child with the safety and convenience you would expect from the #1 mfg.

Vail Products, Inc
235 First St
Toledo, OH 43065
(800) 235-8245 Fax: (419) 698-1174
See our ad on page 81
Circle #41

BICYCLES/TRICYCLES

AngleTech Cycles
318 N Highway 67
PO Box 1893
Woodland Park, CO 80866
(719) 687-7475 Fax: (719) 687-7475

Colombo USA
67 Emerald St
Keene, NH 03431
(603) 358-0439 Fax: (603) 358-0453

Cycletote Corp
Bicycle Trailer-Jogger/Stroller
Ft. Collins, CO 80524
(800) 447-2407 Fax: (970) 482-2402

Haverich Ortho-Sport
67 Emerald St
Keene, NH 03431
(603) 358-0438 Fax: (603) 352-7998
See our ad on page 105
Circle #173

Just Two Bikes, Inc
4821 Washington Ave
White Bear Lake, MN 55110
(800) 499-1548 Fax: (612) 683-9444

Rifton
PO Box 901
Rifton, NY 12471
(800) 374-3866 Fax: (800) 336-5948
See our ad on page 57
Circle #45

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Trailmate
2359E Trailmate Dr
Sarasota, FL 34243
(800) 777-1034 Fax: (800) 477-5141
See our ad on page 4
Circle #195

Triaid, Inc
PO Box 1364
Cumberland, MD 21502
(800) 306-6777 Fax: (301) 759-3525

Viewpoint Manufacturing, Inc
PO Box 108
Spanish Fork, UT 84660
(801) 798-0181 Fax: (801) 489-9533
See our ad on page 78
Circle #167

CLOTHES, SPECIAL

Adrian's Closet
PO Box 9930
Rancho Santa Fe, CA 92067
(800) 831-2577 Fax: (619) 759-0578

Aviano USA (prev Avenues Unltd)
1199-K Ave
Acaso Camarillo, CA 93012
(805) 484-8138 Fax: (805) 484-9789
Apparel and accessories for wheelchair-users. Send $2 for 20 pg catalog, you will receive a $2 discount coupon for the 1st order.

eSpecials-Down Syndrome
PO Box 1177
Larkspur, CA 94977
(415) 924-7960 Fax: (415) 927-9043

Kotton Koala
908 W Moffett Cr Rd
Ft Jones, CA 96032
(916) 468-5475 Fax: (916) 468-5492
See our ad on page 91
Circle #102

M.J. Markell Shoe Co
504 Saw Mill River Rd
Yonkers, NY 10701
(914) 963-2258 Fax: (914) 963-9293
See our ad on page 6
Circle #209

COMPUTER HARDWARE & ACCESSORIES

AdapTek Interface
4832 E Mercer Wy
Mercer Island, WA 98040-4736
(206) 230-0076 Fax: (206) 230-0076

EKEG Electronics Co Ltd
PO Box 46199, Sta D
Vancouver, BC CANADA V6J 5G5
(604) 857-0828 Fax: (604) 857-2726

Equal Access Computer Tech, Inc
39 Oneida Rd
Acton, MA 01720
(508) 263-6437 Fax: (508) 263-6537
Unique forms of switches, such as splint-mounted, touch-sensitive, etc. For those who have difficulty using ordinary switches.

In Touch Systems
11 Westview Rd
Spring Valley, NY 10977
(800) 332-MAGIC or (914) 354-7431
See our ad on page 100
Circle #61

Innocomp
26210 Emery Rd
Warrenville, OH 44128
(216) 464-3636 Fax: (216) 464-3638
See our ad on page 80
Circle #250
The BlinkSwitch is a switch which can be used with anything that can be accessed by a single switch.

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1984 Fax: (216) 263-4829

RJ Cooper & Associates
24843 Del Prado, #283
Dana Pt, CA 92629
(800) R-J-COOPER Fax: (714) 240-9785
See our ad on page 87
Circle #94

Toys For Special Children/Enabling Dvcs
385 Warburton Ave
Hastings, NY 10706
(914) 478-0960 Fax: (914) 478-7030
See our ad on page 106
Circle #149

DRIVING AIDS

Crow River Industries
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688 Fax: (612) 557-8310
See our ad on page 99
Circle #190

Freedom Vans, Inc
1717 NE 32nd Ave
Ocala, FL 34470
(352) 622-9133 Fax: (352) 622-7569

EDUCATIONAL MATERIALS

Academic Therapy Publications
20 Commercial Blvd
Navato, CA 94949
(415) 883-3314 Fax: (415) 883-3720
Great Resource: "No One to Play With: Social Problems of LD and ADD Children." problems/situations with advice for handling them.

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 02136
(413) 528-2523 Fax: (413) 528-0293
See our ad on page 60
Circle #176

Broderbund Software
PO Box 6125
Novato, CA 94948-6125
(800) 521-6263 Fax: (415) 382-4419
See our ad on page 15
Circle #192
Look to Broderbund for dynamic, award-winning educational software for all ages.

Child Development Media, Inc
5632 Van Nuys Blvd, Ste 286
Van Nuys, CA 91401
(800) 405-8942 Fax: (818) 994-0153
See our ad on page 110
Circle #54

Clinicians View
6007 Osuna Rd NE
Albuquerque, NM 87109
(505) 880-0058 Fax: (505) 880-0059
Clinical videos for therapists & parents from pediatrics to home care. Ask us for a catalog & info on internet/900 parent line/ & more.

Crotched Mountain Rehab Center
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311 Fax: (603) 547-6212
See our ad on page 93
Circle #134

Devereux
19 S Waterloo Rd
Devon, PA 19333
(610) 964-3030 Fax: (610) 971-4600
See our ad on page 75
Circle #198

Edmark Corporation
PO Box 97021
Redmond, WA 98073-9721
(800) 362-2890 Fax: (206) 556-8430
See our ad on page 90
Circle #2

Hanen Centre
PO Box 1213, Dept EPJ
Buffalo, NY 14240-1213
(416) 921-1073 Fax: (800) 380-3355
See our ad on page 92
Circle #194

Learning disAbilities Resources
PO Box 716
Bryn Mawr, PA 19010
(800) 869-8336 Fax: (610) 525-8337
Free catalog for reading, writing and math. Instructional materials for L.D.

Meyer Rehabilitation Institute
600 S 42nd St, UNMC
Omaha, NE 68198-5450
(402) 559-7467 Fax: (402) 559-5737
See our ad on page 124
Circle #189

Open Minds™
PO Box 21325
Columbus, OH 43221-0325
(614) 486-4441 Fax: (614) 486-6532
See our ad on page 6
Circle #119

Paynter Educational Partners
6763 Hwy 6 S, Ste 1100-336
Houston, TX 77083-1511
(800) 555-6159

PCI Educational Publishing
5221 McCullough Ave
San Antonio, TX 78212
(800) 594-4263 Fax: (210) 824-8055
See our ad on page 77
Circle #121

Real Life Storybooks
8370 Kentland Ave
West Hills, CA 91304
(800) 999-5668 Fax: (818) 887-6431

Techno Genesis, Inc
PO Box 11976
Prescott, AZ 86304-1976
(520) 778-5611 Fax: (520) 778-2423
"High Tech/Low Cost" book & video show how to build AT devices plus 12 strategies to save $$$ on AT. Expanded 1996 Ed. Free Brochure.

Woodbine House
6510 Bells Mill Rd
Bethesda, MD 20817
(800) 843-7323 Fax: (301) 897-5838

ENVIRONMENTAL CONTROLS

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #30

Prentke Romich Company
1022 Heyl Rd
Wooster, OH 44691
(800) 262-1984 Fax: (216) 263-4829

Quality Air
2487 Via Oeste Dr
Fallbrook, CA 92028
(619) 728-1039
Air purification systems reduces odors, bacteria and pollen. Helps to remove mold and mildew. No filters.

Toys For Special Children/Enabling Dvcs
385 Warburton Ave
Hastings, NY 10706
(914) 478-0960 Fax: (914) 478-7030
See our ad on page 106
Circle #152

FINANCE/ESTATE PLANNING/INSURANCE

The New England
501 Boylston St
Boston, MA 02116-3700
(800) 827-3173
We can help you address your unique financial challenge to guarantee a secure future for your special needs child.

PaineWebber, Inc/Ken Horwitz
1201 3rd Ave, Ste 2400
Seattle, WA 98101
(800) 242-7526 Fax: (206) 447-2492
See our ad on page 6
Circle #107

Protective Life Insurance Company
PO Box 2606
Birmingham, AL 35202
(800) 866-3555 Fax: (205) 868-3996
See our ads on pages 50, 51
Circle #226
Insurance company with a special interest in and concern for the needs of persons with disabilities and their families.

FOOD & NUTRITION

Milani Foods
2525 W Armitage Ave
Melrose Park, IL 60160
(708) 450-3189 Fax: (708) 450-3354
See our ad on page 24
Circle #235
THICK-IT Healthcare food thickener for people with swallowing problems.

HEADGEAR

Plum Enterprises, Inc
PO Box 283
Worchester, PA 19490
(800) 321-PLUM Fax: (610) 584-4151
See our ad on page 83
Circle #86

HOBBIES AND TOYS

Educo International, Inc
123 Cree Rd
Sherwood Park, Alberta
CANADA T3A 3X9
(800) 661-1142 Fax: (403) 467-9772
Award winning manufacturer of handcrafted educational toys. Therapeutic, rehabilitation aids to challenge children & adults.

BEST COPY AVAILABLE

Mommy Daddy Doll (Photo Face)
PO Box 487-E
Flourtown, PA 19031
(800) 323-9365
13" Cotton Doll w Hooded Suit & Your Friendly Face. Send Clear Photo + $18.99, photo returned. For The Times You Can't Be There.

Toys For Special Children/Enabling Dvcs
38a Warburton Ave
Hastings, NY 10706
(914) 478-0960 Fax: (914) 478-7030
See our ad on page 106
Circle #150

Voicing!
3857 Birch, Ste 194
Newport Beach, CA 92660
(800) TOBYTALK Fax: (714) 833-1005

HOME ADAPTATION/DESIGN

Barrier Free Lifts®, Inc
9230 Prince William St
Manassas, VA 22110
(800) 582-8732 Fax: (703) 361-7861
See our ad on page 80
Circle #37

Bruno Independent Living Aids, Inc
1780 Executive Dr - PO Box 84
Oconomowoc, WI 53066
(800) 882-8184 Fax: (414) 567-4341
See our ad on page 25
Circle #241

National Access Products
540 W Boston Post Rd
Mamaroneck, NY 10543-3437
(800) 285-7814 Fax: (800) 285-2525
See our ad on page 91
Circle #11

Oak Hill School
120 Holcomb St
Hartford, CT 06112
(860) 242-2274 Fax: (860) 242-3103
See our ad on page 113
Circle #160

Open Sesame Door Systems
1933 Davis St, #279
San Leandro, CA 94577
(800) OPEN-911
See our ad on page 100
Circle #109

HOME HEALTH CARE SERVICES

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612 Fax: (310) 305-1718
See our ad on page 8
Circle #70

MOMS Catalog
24700 Ave Rockefeller
Valencia, CA 91355
(800) 232-7443 Fax: (800) 622-3429
See our ad on page 64
Circle #205

Olsten Kimberly QualityCare
175 Broad Hollow Rd
Melville, NY 11747
(800) 66-NURSE Fax: (508) 383-7514
See our ad on page 79
Circle #178

INCONTINENCE PRODUCTS

Access Medical Supply
2006 Crown Plaza Dr
Columbus, OH 43235
(800) 242-2460 Fax: (614) 451-9522

ARC Home Health Products
3 Browne St
Oneonta, NY 13820
(800) 278-8595 Fax: (607) 433-6745
See our ad on page 87
Circle #56

Connetquot West, Inc
170 Wilbur Pl
Bohemia, NY 11716
(800) 719-0711
See our ad on page 14
Circle #222
Say Yes to Top Quality & Savings on All Your Incontinent Needs:
•Briefs •Bedpads •Liners
•Training Pants •Skin Care

G. Hirsch & Co (Secure)
1815 Rollins Rd
Burlingame, CA 94010
(800) 638-8800 Fax: (415) 692-1874

Home Delivery Incontinent Supply
1215 Dielman Industrial Ct
Olivette, MO 63132
(800) 289-4663 Fax: (314) 997-0047
See our ad on page 96
Circle #14

Humanicare International, Inc
1471 Jersey Ave
North Brunswick, NJ 08902
(800) 631-5270
Dignity for adults & children include genderized protective garments, pads, guards, undergarments, adult diapers & underpants.

Kimberly-Clark Corporation
PO Box 2020
Neenah, WI 54957-2020
(800) 544-1847
See our ad on page 26
Circle #253

MOMS Catalog
24700 Ave Rockefeller
Valencia, CA 91355
(800) 232-7443 Fax: (800) 622-3429
See our ad on page 64
Circle #206

Principle Business Enterprises, Inc
Pine Lake Industrial Park
Dunbridge, OH 43414
(800) 467-3224 Fax: (419) 352-8340
See our ad on page 59
Circle #129

Promise® Products-Direct Delivery
PO Box 79603
Houston, TX 77279-9603
(800) 659-8037 Fax: (713) 869-5586

Special Products
212 N Market, Ste 315
Wichita, KS 67202
(800) 553-3492
See our ad on page 105
Circle #12

U.S. Medical Corp
14575 Manchester Rd
Manchester, MO 63011
(800) 408-7633 Fax: (314) 394-8136

Woodbury Products
4410 Austin Blvd - Dept 250
Island Park, NY 11558
(800) 777-1111 Fax: (516) 431-6793
See our ad on page 4
Circle #124

FURNITURE

Adaptive Design Labs
15 Standish Ave West
Orange, NJ 07052
(201) 736-4443 Fax: (201) 736-3673
See our ad on page 76
Circle #23

Kids In Mind by Goshen
PO Box 532
Fairlawn, NJ 07410
(800) 286-8181 Fax: (201) 797-2676
See our ad on page 87
Circle #105

R.E.A.L. Design
3 Brayton Ct
Dolgeville, NY 13329
(315) 429-3071 Fax: (315) 429-3071
See our ad on page 137
Circle #52

Vail Products, Inc
235 First St
Toledo, OH 43065
(800) 235-8245 Fax: (419) 698-1174
See our ad on page 81
Circle #42

Kids feel so good, so soon!
NEW!
Children's Laxative
Senokot
Natural Vegetable Laxative
Senokot® Children's Natural Vegetable Laxative Syrup. It's Alcohol-Free.
Use Only As Directed © 1995 The Purdue Frederick Company
Circle #260

LISTENING AIDS/HEARING AIDS

Oticon, Inc
29 Schoolhouse Rd
Somerset, NJ 08875
(800) 526-3921 Fax: (908) 560-0029
Manufacturer of MultiFocus, MicroFocus & world's first fully digital BTE hearing aid DigiFocus, avail. Spring of 96. Oticon 4 Kids.

Sennheiser
6 Vista Dr - PO Box 987
Old Lyme, CT 06371
(860) 434-9190 (V/TDD) Fax: (860) 434-9022
See our ad on page 79
Circle #154

Siemens Hearing Instruments
16 E Piper Ln, Ste 128
Prospect Heights, IL 60070
(800) 333-9083
Hearing Aids; Alerting, Assistive Listening Devices, Amplified Phones & TDDs, Personal Communicators.

MEDICAL EQUIPMENT DEALERS

MOMS Catalog
24700 Ave Rockefeller
Valencia, CA 91355
(800) 232-7443 Fax: (800) 622-3429
See our ad on page 64
Circle #207

The Outlet
216 State St
Santa Barbara, CA 93101
(800) 599-3783 Fax: (805) 899-2854

Positive Image Orthotics
1002 Commons Wy
Toms River, NJ 08755
(908) 286-0690 Fax: (908) 286-4445
See our ad on page 88
Circle #20

U.S. Medical Corp
14575 Manchester Rd
Manchester, MO 63011
(800) 408-7633 Fax: (314) 394-8136

PERSONAL CARE PRODUCTS

Collis Curve
302 N Central Ave
Brownsville, TX 78521
(800) 298-4818 Fax: (210) 546-4818
See our ad on page 94
Circle #144

Nu-Tec Health Products, Inc
390 Oak Ave, Ste A
Carlsbad, CA 92008
(800) 868-8338 Fax: (619) 720-2226
Into-Dent finger toothbrush cleans teeth, massages gums and stimulates. Fits adult finger & maneuvers easily throughout mouth. Call 800-868-8338.

NR Laboratories, Inc.
900 E Franklin St
Centerville, OH 45459-5620
(513) 433-9570 Fax: (513) 433-0779
See our ad on page 114
Circle # 269

Oralgiene USA, Inc
421 N Rodeo Dr, Ste 15114
Beverly Hills, CA 90210
(800) 933-ORAL Fax: (310) 824-6350
See our ad on page 63
Circle #255

PHARMACEUTICAL PROD/SVCS

DEY Laboratories
2751 Napa Valley Corporate Dr
Napa, CA 94558
(707) 224-3200 Fax: (707) 224-8918
See our ad on page 5
Circle #115
DEY Laboratories is dedicated to helping people who suffer from respiratory diseases breathe easier.

Milani Foods
2525 W Armitage Ave
Melrose Park, IL 60160
(708) 450-3189 Fax: (708) 450-3354
See our ad on page 24
Circle #236
THICK-IT Healthcare food thickener for people with swallowing problems.

Preferred RX of Ohio
34208 Aurora Rd, Ste 132
Solon, OH 44139
(800) 843-7038 Fax: (216) 247-9313
See our ad on page 14
Circle # 270

Purdue Frederick Company
100 Connecticut Ave
Norwalk, CT 06850
(800) 733-1333 or (203) 853-0123
See our ad on page 135
Circle #260
Senokot children's laxative syrup standardized senna concentrate natural vegetable laxative comfortable overnight relief.

PUBLISHERS/CATALOGS

Abilitations by Sportime Intl
One Sportime Way
Atlanta, GA 30340
(800) 850-8602 Fax: (800) 845-1535
See our ad on page 114
Circle #238

Charles C. Thomas
2600 S First St
Springfield, IL 62794-9265
(800) 258-8980 Fax: (217) 789-9130
See our ad on page 72
Circle #254

Jason & Nordic
PO Box 4411
Hollidaysburg, PA 16648
(814) 696-2920 Fax: (814) 696-4250

MOMS Catalog
24700 Ave Rockefeller
Valencia, CA 91355
(800) 232-7443 Fax: (800) 622-3429
See our ad on page 64
Circle #208

NCM Consumer Products Division
PO Box 6070
San Jose, CA 95150
(800) 235-7054 Fax: (408) 2[illegible]24

Open Minds™
PO Box 21325
Columbus, OH 43221-0325
(614) 486-4441 Fax: (614) 486-6532
See our ad on page 6
Circle #120

The Prader-Willi Perspectives
40 Holly Ln
Roslyn Heights, NY 11577
(800) 358-0682 Fax: (516) 484-7154
See our ad on page 126
Circle #25

Special Needs Project
3463 State St
Santa Barbara, CA 93105
(800) 333-6867 Fax: (805) 683-2341
See our ad on page 142
Circle #274
Special Needs Project world wide-leader in disability info resources offers comprehensive book lists for over 1,000 publishers.

Woodbine House
6510 Bells Mill Rd
Bethesda, MD 20817
(800) 843-7323 Fax: (301) 897-5838
An outstanding series of books about children and disabilities for parents and service providers. Call (800) 843-7323 for a free catalog.

RAMPS/LIFTS

Barrier Free Lifts®, Inc
9230 Prince William St
Manassas, VA 22110
(800) 582-8732 Fax: (703) 361-7861
See our ad on page 80
Circle #38

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT Fax: (219) 946-4670
See our ads on pages 21, 23
Circle #78
The Braun Corp is the intl leader in mobility prdcts & has a worldwide distrib ntwrk. Positioned to provide equipment & services you need.

Bruno Independent Living Aids, Inc
1780 Executive Dr - PO Box 84
Oconomowoc, WI 53066
(800) 882-8184 Fax: (414) 567-4341
See our ad on page 25
Circle #240

Crow River Industries
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688 Fax: (612) 557-8310
See our ad on page 99
Circle #180

Freedom Vans, Inc
1717 NE 32nd Ave
Ocala, FL 34470
(352) 622-9133 Fax: (352) 622-7569

Hig's Aluminum Products
10625 Maple Ln
Rogers, MN 55374
(612) 498-7304 Fax: (612) 498-7022

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(800) 322-2884 Fax: (818) 890-3354
See our ad on page 58
Circle #88

Sure Hands™ Lift & Care Systems
982 Route 1
Pine Island, NY 10969
(800) 724-5305 Fax: (914) 258-6634
See our ad on page 74
Circle #53

Vantage Minivans
5214 S 30th St
Phoenix, AZ 85040-3730
(800) 348-8267 Fax: (602) 243-9843
See our ad on the inside back cover
Circle #166

Wheelers, Inc
7101 N 55th Ave
Glendale, AZ 85301
(800) 456-1371 Fax: (602) 435-9989
See our ad on page 77
Circle #228

REHAB CENTERS/HOSPITALS

Bancroft
Hopkins Ln
Haddonfield, NJ 08033
(609) 429-0010 Fax: (609) 429-1613
See our ad on page 76
Circle # 276

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 02136
(413) 528-2523 Fax: (413) 528-0293
See our ad on page 60
Circle #175

Children's Seashore House
3405 Civic Center Blvd
Philadelphia, PA 19104
(800) 678-3773 Fax: (215) 895-3600
See our ad on page 121
Circle #218
Rehabilitation/Child Development ADHD/Communication Disorders/Behavioral Pediatrics/Neurorehab/Medical Compliance/Feeding Mngt.

Children's Specialized Hospital
150 New Providence Rd
Mountainside, NJ 07092-2590
(908) 233-3720 Fax: (908) 233-4176
See our ad on page 109
Circle #63

Crotched Mountain Rehab Center
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311 Fax: (603) 547-6212
See our ad on page 93
Circle #133

Cumberland Hospital
9407 Cumberland Rd
New Kent, VA 23124
(800) 368-3472
See our ad on page 114
Circle #221

Devereux
19 S Waterloo Rd
Devon, PA 19333
(610) 964-3030 Fax: (610) 971-4600
See our ad on page 75
Circle #197

Gillette Children's Hospital
200 E University Ave
St Paul, MN 55101
(612) 291-2848 Fax: (612) 229-3833
See our ad on page 59
Circle #224

Health Hill Hospital for Children
2801 Martin Luther King Jr Dr
Cleveland, OH 44104
(216) 721-5400 Fax: (216) 231-2010
See our ad on page 117
Circle #137

Hospital for Sick Children
1731 Bunker Hill Rd, NE
Washington, DC 20017
(202) 832-4400 Fax: (202) 635-6150
See our ad on page 71
Circle #57
Rehab & Transitional Care for infants to age 21: Cardipul, Nutrition, Develop & Compreh Rehab; Preemie Express & Early Interv.

Kennedy Krieger Institute
707 N Broadway
Baltimore, MD 21205
(800) 873-3377 Fax: (410) 550-8217
See our ad on page 110
Circle #62

New England Center For Autism
P O Box 593
Peabody, MA 01960
(508) 531-6722 Fax: (508) 532-1607
See our ad on page 78
Circle # 268

Olsten Kimberly QualityCare
175 Broad Hollow Rd
Melville, NY 11747
(800) 66-NURSE Fax: (508) 383-7514
See our ad on page 79
Circle #177

Voorhees Pediatric Facility
1304 Laurel Oak Rd
Voorhees, NJ 08043
(609) 346-3300 Fax: (609) 435-4223
See our ad on page 100
Circle #24

Walton Rehabilitation Hospital
1355 Independence Dr
Augusta, GA 30901-1037
(800) 332-4544 or (706) 724-7746
See our ad on page 73
Circle #220

SCHOOLS/CAMPS/RESIDENCES

Adaptive Sports & Recreation
2279 Rowland Ave
Simi Valley, CA 93063
(805) 581-4706 Fax: (805) 581-1220

Anne Carlsen Center for Children
301 7th Ave NW
Jamestown, ND 58401
(800) 568-5175 Fax: (701) 252-3850
See our ad on page 4
Circle #128
Serving children with CP, Autism, TBI, birth defects, & multiple disabilities. Program includes life skills, therapy, medical & residential care; summer camps.

Bancroft
Hopkins Ln
Haddonfield, NJ 08033
(609) 429-0010 Fax: (609) 429-1613
See our ad on page 76
Circle # 275

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 02136
(413) 528-2523 Fax: (413) 528-0293
See our ad on page 60
Circle #174

Camp Courageous of Iowa
Open Year-Round/Special Needs
Monticello, IA 52310-0418
(319) 465-5916 Fax: (319) 465-5919

Camp Huntington
55 Ricks Rd
Woodstock, NY 12498
(914) 679-4903 Wint Fax: (914) 687-7211

Camp Thunderbird
PO Box 1300
Apopka, FL 32704
(407) 889-8088 Fax: (407) 889-8072
ACA Accredited residential summer camp (Orlando area) for children & adults who have a developmental disability. Focus on self-esteem.

Camphill Special School
1784 Fairview Rd
Glenmoore, PA 19343
(610) 469-9236 Fax: (610) 469-9758
Non-institutional, children's village, residential/day; extensive therapies; focus on arts/Waldorf curriculum; pool, equestrian therapy, festivals.

Chapel Haven
1040 Whalley Ave
New Haven, CT 06515
(203) 397-1714 Fax: (203) 397-8004
An independent living program located in New Haven, Chapel Haven offers a continuum of services for persons with learning disabilities.

Children First
824 S Main St
Ada, OH 45810-1507
(419) 634-9232
See our ad on page 6
Circle #249

Children's Care Hospital & School
2501 W 26th St
Sioux Falls, SD 57105
(800) 584-9294 Fax: (605) 336-0277

Crotched Mountain Rehab Center
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311 Fax: (603) 547-6212
See our ad on page 93
Circle #132

Devereux
19 S Waterloo Rd
Devon, PA 19333
(610) 964-3030 Fax: (610) 971-4600
See our ad on page 75
Circle #196

Evergreen Center
345 Fortune Blvd
Milford, MA 01757
(508) 478-2631 Fax: (508) 634-3251
See our ad on page 125
Circle #131

Githens Center for Phys Disabled
40 Cedar St
Mt Holly, NJ 08060
(609) 261-1667 Fax: (609) 261-1844

Groden Center
86 Mount Hope
Providence, RI 02906
(401) 274-6310 Fax: (401) 421-3280
See our ad on page 74
Circle #170
Offering day and residential treatment, education and vocational programs for children and adults with autism and other behavioral disabilities.

Heartspring
2400 Jardine Dr
Wichita, KS 67219-4699
(800) 835-1043 Fax: (316) 262-0170
See our ad on page 11
Circle #155

HMS School for Children with CP
4400 Baltimore Ave
Philadelphia, PA 19104
(215) 222-2566 Fax: (215) 222-1889
See our ad on page 120
Circle #200

IDDI, Crystal Springs School
38 Narrows Rd
Assonet, MA 02702-0372
(508) 644-3101 Fax: (508) 644-3101 ext 372
See our ad on page 126
Circle #265

Ivy Street School
200 Ivy St
Brookline, MA 02146
(617) 732-0224 Fax: (617) 738-1247
Provide comprehensive special education, clinical, behavioral and vocational services to adolescents who have acquired brain injuries.

Language & Cognitive Dvlp Ctr
PO Box 27011 Wyman St
Boston, MA 02130
(617) 522-5434 Fax: (617) 522-9631
See our ad on page 76
Circle #67

LARC School
1089 Creek Rd
Bellmawr, NJ 08031-1648
(609) 933-3725 Fax: (609) 933-3158
LARC School provides educational/ therapeutic, pre-vocational and recreational services to Developmentally Delayed & Multiple-Handicapped students 5-21.

real solutions

real needs

real design

Rehab and Educational Aids for Living

R.E.A.L. DESIGN

3 Brayton Court
Dolgeville, NY 13329
Phone and Fax: 315-429-3071

139 Circle #50

Freedom Designs, Inc.

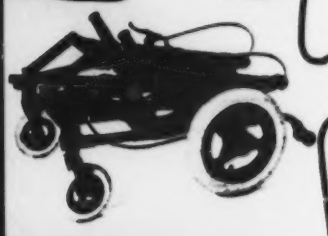
Not just another piece of the puzzle.

The Solution

TILT IN SPACE
Our tilt in space feature is easy to operate.

RECLINE
The Solution *offers an incremental recline.*

LE
ign folds
n ease.



TILT AND RECLINE
The frame can be reclined and tilted simultaneously.

om Designs, Inc. 2241 Madera Road ◆ Simi Valley, CA 93065
one (800) 331-8551 ◆ (805) 582-0077 ◆ Fax (805) 582-1509

Circle #138

League School of Boston
225 Nevada St
Newtonville, MA 02160
(617) 964-3260 Fax: (617) 964-3264
See our ad on page 105
Circle #158

The Learning Center
411 Waverly Oaks Rd
Waltham, MA 02154
(617) 893-6000 Fax: (617) 893-1171

Lukas Community
PO Box 137
Temple, NH 03084
(603) 878-4111 Fax: (603) 878-4111
See our ad on page 14
Circle #219

Martha Lloyd Community Services For People with Mental Retardation
Troy, PA 16947
(717) 297-2185
See our ad on page 56
Circle #157

National Information Hotline Svc for MR Prog
c/o Bethesda Home
Watertown, WI 53094
(800) 369-4636
See our ad on page 142
Circle #136

New England Villages
664 School St
Pembroke, MA 02359
(617) 293-5461 Fax: (617) 837-4094
See our ad on page 124
Circle #158

Oak Hill School
120 Holcomb St
Hartford, CT 06112
(860) 242-2274 Fax: (860) 242-3103
See our ad on page 113
Circle #159

St Coletta's of Massachusetts
400 Washington St
Hanover, MA 02339
(617) 826-6371 Fax: (617) 826-6474
See our ad on page 124
Circle #171

Stewart Home School
4200 Lawrenceburg Rd
Frankfort, KY 40601
(502) 227-4821 Fax: (502) 227-3013
See our ad on page 95
Circle #164

YAI
460 W 34th St, 11th fl
New York, NY 10001
(212) 563-7474 Fax: (212) 268-1083
A network of programs providing early interv/clinical/fam support rec/camp/employ/resid svcs to persons of all ages with MR/DD/LD.

SCOOTERS

Bruno Independent Living Aids, Inc
1780 Executive Dr - PO Box 84
Oconomowoc, WI 53066
(800) 882-8184 Fax: (414) 567-4341
See our ad on page 25
Circle #242

SEATING AND POSITIONING

Adaptive Design Labs
15 Standish Ave
West Orange, NJ 07052
(201) 736-4443 Fax: (201) 736-3673
See our ad on page 76
Circle #22

Barrier Free Lifts®, Inc
9230 Prince William St
Manassas, VA 22110
(800) 582-8732 Fax: (703) 361-7861
See our ad on page 80
Circle #39

Beatrice M. Brantman, Inc
207 E Westminster
Lake Forest, IL 60045
(800) 232-7987 Fax: (708) 615-8894
See our ad on page 110
Circle #233
Completely portable transfer systems made of space age materials, which provide for a safe, controlled lateral slide-NO MORE LIFTING!

Better Baby Products, Inc
10 Basswood Dr
Denville, NJ 07834
(800) SIT-2-IN-1 Fax: (201) 625-8006
See our ad on page 125
Circle #146

Bruno Independent Living Aids, Inc
1780 Executive Dr - PO Box 84
Oconomowoc, WI 53066
(800) 882-8184 Fax: (414) 567-4341
See our ad on page 25
Circle #243

Child Quest, Inc SeatKeeper
PO Box 18595
Austin, TX 78760
(800) 732-8533 Fax: (800) 558-2002
See our ad on page 88
Circle #81

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612 Fax: (310) 305-1718
See our ad on page 8
Circle #71

Convaid Products, Inc
PO Box 4209
Palos Verdes, CA 90274
(800) 552-3670 Fax: (310) 539-5814
See our ad on page 3
Circle #65

E-Z-ON Products, Inc of Florida
500 Commerce Way W
Jupiter, FL 33458
(800) 323-6598 Fax: (407) 747-8779
See our ad on page 90
Circle #185

Freedom Designs, Inc
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551 Fax: (805) 582-1509
See our ad on page 138
Circle #139

Gillette Children's Hospital
200 E University Ave
St Paul, MN 55101
(612) 291-2848 Fax: (612) 229-3833
See our ad on page 59
Circle #225

Innovative Products
830 S 48th St
Grand Forks, ND 58201
(701) 772-5185 Fax: (701) 772-5224
See our ad on page 94
Circle #247

Invacare Corp
899 Cleveland St
Elyria, OH 44036
(800) 333-6900 or (216) 329-6000
PinDot®; ContourU™ Silhouette®.

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #31

Kids In Mind by Goshen
PO Box 532
Fairlawn, NJ 07410
(800) 286-8181 Fax: (201) 797-2676
See our ad on page 87
Circle #106

Leckey
360 Merrimack St, Bldg 5
Lawrence, MA 01843
(508) 691-5220 Fax: (508) 691-5230

Mulholland Positioning Systems, Inc
PO Box 391 - 215 N 12th St
Santa Paula, CA 93061
(805) 525-7165 Fax: (805) 933-1082
See our ad on page 81
Circle #74

Oak Hill School
120 Holcomb St
Hartford, CT 06112
(860) 242-2274 Fax: (860) 242-3103
See our ad on page 113
Circle #161

R.E.A.L. Design
3 Brayton Ct
Dolgeville, NY 13329
(315) 429-3071 Fax: (315) 429-3071
See our ad on page 137
Circle #51

Rifton
PO Box 901
Rifton, NY 12471
(800) 374-3866 Fax: (800) 336-5948
See our ad on page 57
Circle #47

Snug Seat, Inc
PO Box 1739
Matthews, NC 28106
(800) 336-7684 Fax: (704) 847-9577
See our ad on page 22
Circle #212

Special Designs, Inc
PO Box 130
Gillette, NJ 07933
(908) 464-8825 Fax: (908) 464-8251
See our ad on page 109
Circle #216

Supracor Systems, Inc
1135 E Arques Ave
Sunnyvale, CA 94086
(408) 732-1818 Fax: (408) 732-2317
Supracor introduces its machine washable Stimulite® Honeycomb Corbee™ Cushion which provides Total Pressure Management™ for kids.

Tumble Forms
145 Tower Dr
Burr Ridge, IL 60521
(800) 323-5547 Fax: (800) 547-4333
See our ad on the back cover
Circle #180

Unishape Positioning System
1630 30th St, Ste 202
Boulder, CO 80301
(303) 443-8348 Fax: (303) 443-3136
See our ad on page 81
Circle #172

SOFTWARE

Apple Computer
Disability Solutions
One Infinite Loop, M/S 38-DS
Cupertino, CA 95014
(800) 600-7808 or (800) 755-0601 (TTY)
See our ad on page 11

Broderbund Software
PO Box 6125
Novato, CA 94948-6125
(800) 521-6263 Fax: (415) 382-4419
See our ad on page 15
Circle #193
Look to Broderbund for dynamic, award-winning educational software for all ages.

Edmark Corporation
PO Box 97021
Redmond, WA 98073-9721
(800) 362-2890 Fax: (206) 556-8430
See our ad on page 90
Circle #3

Laureate Learning Systems, Inc
110 E Spring St
Winooski, VT 05404
(800) 562-6801 or (802) 655-4755
See our ad on page 83
Circle #85

Meeting The Challenge
3630 Sinton Rd, Ste 103
Colorado Springs, CO 80907
(719) 444-0252 Fax: (719) 444-0269

RJ Cooper & Associates
24843 Del Prado, #283
Dana Pt, CA 92629
(800) R-J-COOPER Fax: (714) 240-9785
See our ad on page 87
Circle #96

Sentient Systems Technology, Inc
2100 Wharton St, Ste 630
Pittsburgh, PA 15203
(800) 344-1778
Fax: (412) 381-5241
See our ad on page 84
Circle #112
Sentient Systems offers advanced communication devices & software for preschoolers, students & adults who have difficulty speaking.

SoftTouch/kidTECH
4182 Pinewood Lake
Bakersfield, CA 93309
(805) 396-8676 Fax: (805) 396-8760
See our ad on page 124
Circle #153

Technology For Education, Inc
2300 Lexington Ave S, Ste 202
St Paul, MN 55120
(612) 686-5678 Fax: (612) 454-8108
See our ad on page 105
Circle #191

SPORTS/RECREATION/FAMILY

Airlift Unlimited, Inc
1212 Kerr Gulch
Evergreen, CO 80439
(800) 776-6771 Fax: (303) 526-1760
Parents! Carry baby's oxygen in Air Lift backpack and your baby in your arms. Also, backpacks sized for the oxygen dependent child.

Baby Jogger Co dba Racing Stroller
2609 River Rd
Yakima, WA 98902
(509) 457-0925 Fax: (509) 453-7732
See our ad on page 114
Circle #96

Ball Dynamics International, Inc
1616 Glenarm Pl. Ste 1900
Denver, CO 80202
(800) 752-2255 Fax: (303) 893-0524
See our ad on page 70
Circle #127
BDI features books and videos on ball exercise programs as well as Gymnic balls, rolls, seating cushions and massage balls.

BAMI, Inc
5930 Lillian St
Los Angeles, CA 90001
(213) 585-4111 Fax: (213) 965-5522
See our page on page 74
Circle #108

Blackberry Technology
3813 Countryville Rd
Countryville, PA 19465
(800) 413-4824 Fax: (610) 469-9268
See our ad on page 109
Circle #8

Blue Sky Cycle Carts
PO Box 5788
Bend, OR 97708
(541) 383-7109
See our ad on page 91
Circle #13

Care Electronics
5741 Arapahoe Rd, Unit 2A
Boulder, CO 80303-1341
(303) 444-2273 Fax: (303) 447-3502
See our ad on page 95
Circle #122

Equipment Shop
PO Box 33
Bedford, MA 01730
(617) 275-7681 Fax: (617) 275-4094
See our ad on page 126
Circle #43

Flaghouse
150 N Mac Questen Pkwy
Mt Vernon, NY 10550
(800) 793-7900 Fax: (800) 793-7922
See our ads on pages 34, 35, 92
Circle #145

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #32

Just Two Bikes, Inc
4821 Washington Ave
White Bear Lake, MN 55110
(800) 499-1548 Fax: (612) 683-9444

Oak Hill School
120 Holcomb St
Hartford, CT 06112
(860) 242-2274 Fax: (860) 242-3103
See our ad on page 113
Circle #162

Sony Rec & Energy Prod Group
680 Kinderkamack Rd
Oradell, NJ 07649
(201) 599-3533 Fax: (201) 599-3556
See our ad on page 55
Circle #237

Viewpoint Manufacturing, Inc
PO Box 108
Spanish Fork, UT 84660
(801) 798-0181 Fax: (801) 489-9533
See our ad on page 78
Circle #168

STANDING EQUIPMENT

Axiom/Prime Engineering
4838 W Jacquelyn, #105
Fresno, CA 93722
(209) 276-0991 Fax: (209) 276-3544
See our ad on page 126
Circle #91

Consumer Care Products, Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353 Fax: (414) 459-9070
See our ad on page 92
Circle #16

MOR Foundation
PO Box 662
Bakersfield, CA 93302
(805) 871-8219
See our ad on page 56
Circle #82

Mulholland Positioning Systems, Inc
PO Box 391 - 215 N 12th St
Santa Paula, CA 93061
(805) 525-7165 Fax: (805) 933-1082
See our ad on page 81
Circle #75

Rifton
PO Box 901
Rifton, NY 12471
(800) 374-3866 Fax: (800) 336-5948
See our ad on page 57
Circle #48

Snug Seat, Inc
PO Box 1739
Matthews, NC 28106
(800) 336-7684 Fax: (704) 847-9577
See our ad on page 22
Circle #213

Special Designs, Inc
PO Box 130
Gillette, NJ 07933
(908) 464-8825 Fax: (908) 464-8251
See our ad on page 109
Circle #217

Tumble Forms
145 Tower Dr
Burr Ridge, IL 60521
(800) 323-5547 Fax: (800) 547-4333
See our ad on the back cover
Circle #183

STROLLERS

Baby Jogger Co dba Racing Stroller
2609 River Rd
Yakima, WA 98902
(509) 457-0925 Fax: (509) 453-7732
See our ad on page 114
Circle #97

Columbia Medical Mfg Corp
PO Box 633
Pacific Palisades, CA 90272
(800) 454-6612 Fax: (310) 305-1718
See our ad on page 8
Circle #72

Convaid Products, Inc
PO Box 4209
Palos Verdes, CA 90274
(800) 552-3670 Fax: (310) 539-5814
See our ad on page 3
Circle #66

Freedom Designs, Inc
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551 Fax: (805) 582-1509
See our ad on page 138
Circle #140

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #33

New England Center For Autism
P O Box 593
Peabody, MA 01960
(508) 531-6722 Fax: (508) 532-1607
See our ad on page 78
Circle # 267

Snug Seat, Inc
PO Box 1739
Matthews, NC 28106
(800) 336-7684 Fax: (704) 847-9577
See our ad on page 22
Circle #214

DRESSING TABLE
for your convenience

- dress, change and bathe your child at the right working height
- saves your back
- saves space, as it folds against the wall when not in use
- when fixed in the bathroom it can be used as a shower stretcher
- good quality for a good price
- ideal for Special Education Classrooms and other facilities, as this table will accommodate larger children and young adults.

Call now for details and information on our bathroom safety equipment:
Linido USA Chattanooga, TN, USA 1-800-698-4504

Circle #58

Tumble Forms
145 Tower Dr
Burr Ridge, IL 60521
(800) 323-5547 Fax: (800) 547-4333
See our ad on the back cover
Circle #181

TELEPHONE EQUIPMENT

Hear-More, Inc
PO Box 3413
Farmingdale, NY 11735
(800) 881-4327 (V/TTY)
Fax: (516) 752-0689

TRAVEL/LEISURE/HOTELS

AccessAbility Travel
186 Alewife Brook Pkwy, Ste 310
Cambridge, MA 02138
(617) 661-9941 Fax: (617) 661-3354

VANS

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT Fax: (219) 946-4670
See our ads on pages 21, 23
Circle #79
The Braun Corp is the intl leader in mobility prdcts & has a worldwide distrib ntwrk. Positioned to provide equipment & services you need.

Chrysler Automobility Program
PO Box 3124
Bloomfield Hills, MI 48302-5124
(800) 255-9877
See our ad on page 7
Circle #251

Ford Mobility Motoring Program
PO Box 529
Bloomfield Hills, MI 48303-9857
(800) 952-2248 Fax: (810) 333-2191
See our ad on the inside front cover
Circle #239

G.M. Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935 Fax: (313) 974-4383
See our ad on page 13

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(800) 322-2884 Fax: (818) 890-3354
See our ad on page 58
Circle #89

Vantage Minivans
5214 S 30th St
Phoenix, AZ 85040-3730
(800) 348-8267 Fax: (602) 243-9843
See our ad on the inside back cover
Circle #165

VAN CONVERSIONS

The Braun Corporation
1014 S Monticello St
Winamac, IN 46996
(800) THE-LIFT Fax: (219) 946-4670
See our ads on pages 21, 23
Circle #80
The Braun Corp is the intl leader in mobility prdcts & has a worldwide distrib ntwrk. Positioned to provide equipment & services you need.

Causeway Ford
Route 72 E
Manahawkin, NJ 08050
(609) 597-8083 Fax: (609) 597-6089

Crow River Industries
14800 28th Ave N
Minneapolis, MN 55447
(800) 488-7688 Fax: (612) 557-8310
See our ad on page 99
Circle #188

Drive Master, Inc
9 Spielman Rd
Fairfield, NJ 07004-3403
(201) 808-9709 Fax: (201) 808-9713

G.M. Mobility Assistance Center
PO Box 9011
Detroit, MI 48202
(800) 323-9935 Fax: (313) 974-4383
See our ad on page 13

New Horizon Vans, Inc
3717 High St. NE
Albuquerque, NM 87107
(505) 343-9194 Fax: (505) 343-9196

OCM Handicapped Conversions
750 E Sample Rd, Bldg 8/7
Pompano Beach, FL 33064
(800) 464-8458 Fax: (954) 942-6240

Ricon Corporation
12450 Montague St
Pacoima, CA 91331
(800) 322-2884 Fax: (818) 890-3354
See our ad on page 58
Circle #90

Vantage Minivans
5214 S 30th
St Phoenix, AZ 85040-3730
(800) 348-8267 Fax: (602) 243-9843
See our ad on the inside back cover
Circle #165

Wheelers, Inc
7101 N 55 Ave
Glendale, AZ 85301
(800) 456-1371 Fax: (602) 435-9989
See our ad on page 77
Circle #229

VAN RENTALS

Wheelchair Getaways
PO Box 605
Versailles, KY 40383
(800) 642-2042 Fax: (606) 873-8039
See our ad on page 120
Circle #59

Wheelers, Inc
7101 N 55 Ave
Glendale, AZ 85301
(800) 456-1371 Fax: (602) 435-9989
See our ad on page 77
Circle #230

VISION AIDS

HumanWare, Inc
6245 King Rd
Loomis, CA 95650
(916) 652-7254 Fax: (916) 652-7296
Specializing in products for the blind and visually impaired. Free catalog. CCTV's. Voice Synthesizers, Braille Printers etc.

MAXI-Aids
42 Executive Blvd
Farmingdale, NY 11735
(800) 522-6294 Fax: (516) 752-0689

WALKING AIDS

Consumer Care Products, Inc
PO Box 684
Sheboygan, WI 53082-0684
(414) 459-8353 Fax: (414) 459-9070
See our ad on page 92
Circle #17

Jesana Ltd
979 Saw Mill River Rd
Yonkers, NY 10710
(800) 443-4728 Fax: (914) 376-0021
See our ad on page 91
Circle #34

Triaid, Inc
PO Box 1364
Cumberland, MD 21502
(800) 306-6777 Fax: (301) 759-3525

WHEELCHAIRS, MANUAL

Blackberry Technology
3813 Coventryville Rd
Coventryville, PA 19465
(800) 413-4824 Fax: (610) 469-9268
See our ad on page 109
Circle #7

Colours
1591 S Sinclair St
Anaheim, CA 92806
(800) 892-8998 Fax: (714) 978-2891

Convaid Products, Inc
PO Box 4209
Palos Verdes, CA 90274
(800) 552-3670 Fax: (310) 539-5814
See our ad on page 3
Circle #64

ETAC USA, Inc
2325 Parkiawn Dr, Ste J
Waukesha, WI 53186
(800) 678-3822 Fax: (414) 796-4600
See our ad on page 14
Circle # 223

Freedom Designs, Inc
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551 Fax: (805) 582-1509
See our ad on page 138
Circle #141

Invacare Corp
899 Cleveland St
Elyria, OH 44036
(800) 333-6900 or (216) 329-6000
Action Comet, Action Junior, Action Tiger and Action Allegro

Kid-Kart
732 Cruiser Ln
Belgrade, MT 59714
(800) 388-5278 Fax: (406) 388-1081
See our ad on page 15
Circle # 273

Natural Access All-Terrain Wichrs
430 Kainlu St, Ste 1106
Honolulu, HI 96815
(808) 926-1176 Fax: (808) 926-1176
See our ad on page 95
Circle #125
All-terrain Landeez chair: beach & nature trail accessible. Rolls over sand, gravel and snow just as easily as paved walkways.

Vector Mobility, Inc
5030 E Jensen Ave
Fresno, CA 93725-1807
(800) 441-0358 Fax: (209) 441-0359
See our ad on page 20
Circle #100

WHEELCHAIRS, POWERED

Innovative Products
830 S 48th St
Grand Forks, ND 58201
(701) 772-5185 Fax: (701) 772-5224
See our ad on page 94
Circle #248

Invacare Corp
899 Cleveland St
Elyria, OH 44036
(800) 333-6900 or (216) 329-6000

Permobil, Inc
6B Gill St
Woburn, MA 01801
(800) 736-0925 Fax: (617) 932-0428
See our ad on page 119
Circle #147

Redman Powerchairs
945 E Ohio, #4
Tucson, AZ 85714
(800) 727-6684 Fax: (602) 294-8836
See our page on 94
Circle #163

Vector Mobility, Inc
5030 E Jensen Ave
Fresno, CA 93725-1807 (800) 441-0358
Fax: (209) 441-0359
See our ad on page 20
Circle #101

OTHER

CANOPIES FOR WHEELCHAIRS

Diestco Manufacturing Company
PO Box 5504
Chico, CA 95927
(800) 795-2392 Fax: (916) 893-2535
Circle #263
The WeatherBreaker canopy fits on any wheelchair/stroller/scooter to protect from the sun and rain. (Often 3rd party pre-approved.)

CUSTOM VANS

Vantage Minivans
5214 S 30th St
Phoenix, AZ 85040-3730
(800) 348-8267 Fax: (602) 243-9843
See our ad on the inside back cover
Circle #202

INDEPENDENT LIVING SKILLS

Crotched Mountain Rehab Center
1 Verney Dr
Greenfield, NH 03047
(603) 547-3311 Fax: (603) 547-6212
See our ad on page 93
Circle #135

LIFE SKILLS LEARNING CENTER

Heartspring
2400 Jardine Dr
Wichita, KS 67219-4699
(800) 835-1043 Fax: (316) 262-0170
See our ad on page 11
Circle #203

MINI-VANS

Wheelers, Inc
7101 N 55th Ave
Glendale, AZ 85301
(800) 456-1371 Fax: (602) 435-9989
See our ad on page 77
Circle #231

ORTHOTICS & PROSTHETICS

Positive Image Orthotics
1002 Commons Wy
Toms River, NJ 08755
(908) 286-0690 Fax: (908) 286-4445
See our ad on page 88
Circle #19

STAIRLIFTS

Bruno Independent Living Aids, Inc
1780 Executive Dr - PO Box 84
Oconomowoc, WI 53066
(800) 882-8184 Fax: (414) 567-4341
See our ad on page 25
Circle #244

TECHNOLOGY/ENGINEERING SERVICES

Bio-Nexus, Inc
8 Baypath Wy
Branford, CT 06405
(203) 481-4942 Fax: (203) 481-4797
See our ad on page 94
Circle #49

TRANSFER DEVICES

NCM Consumer Products Division
PO Box 6070
San Jose, CA 95150
(800) 235-7054 Fax: (408) 277-6824

TRANSITIONAL COMMUNITY

Evergreen Center
345 Fortune Blvd
Milford, MA 01757
(508) 478-2631 Fax: (508) 634-3251
See our ad on page 125
Circle #131

TRANSPORTATION VESTS

E-Z-ON Products, Inc of Florida
500 Commerce Way W
Jupiter, FL 33458
(800) 323-6598 Fax: (407) 747-8779
See our ad on page 90
Circle #186

WHEELCHAIR-LIGHTWEIGHT, FOLDING

Freedom Designs, Inc
2241 Madera Rd
Simi Valley, CA 93065
(800) 331-8551 Fax: (805) 582-1509
See our ad on page 138
Circle #142

YEAR-ROUND RESIDENCE

Berkshire Meadows
249 N Plain Rd
Housatonic, MA 02136
(413) 528-2523 Fax: (413) 528-0293
See our ad on page 60
Circle #201

SPECIAL NEEDS PROJECT

Disability Information Resources

Parents! Call now for a free, comprehensive listing of over 100 categories–all about disabilities and related subjects–representing more than 1000 publishers.

•Books
•Periodicals
•Multimedia
•Newletters

•Videos
•Audiotapes
•Product Information

Agencies–Family Resource Centers–Schools! Call now to receive a comprehensive collection of materials including annotated master booklists, programs designed to support your networks, the Book Reward, books on consignment and conference kits.

Information: 805-683-9633 • Orders: 800-333-6867
Fax: 805-683-2341 • Email: snpbooks@eworld.com
3463 State St., #282 • Santa Barbara, CA 93105

WORLD WIDE

Circle #274

Did I Hear You Say Help?

National Christian Resource Center on Mental Retardation
a service of:
Bethesda
LUTHERAN HOMES AND SERVICES, INC.
700 Hoffman Dr.
Watertown, WI 53094
A.L. Napolitano
Executive Director
Call 1-800-369-INFO

☐ Are you looking for appropriate services for yourself, your family member or client?

☐ Would you like to obtain information on religious services and materials offered by specific faith groups and Bethesda?

Then call our toll-free hotline 1-800-369-INFO.

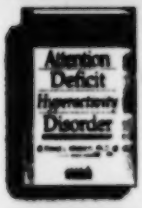
We offer:

- Lists of services in specified geographic areas.
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

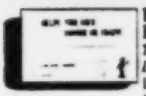
Circle #136

ATTENTION DEFICIT DISORDER



ATTENTION DEFICIT HYPERACTIVITY DISORDER
What Every Parent Wants to Know
D.L. WOODRICH,PH.D.
Prepares parents at home and at school, empowers and re-affirms parents of their role.
PD070AD **$19.95**

ATTENTION DEFICIT DISORDER
ADHD and ADD Syndromes
D.R. JOHNS
A comprehensive guide to ADHD and ADD and its effects and treatment.
PE038AD - BOOK **$18.00**
PE038 - VIDEO **$80.00**



HELP! THIS KID'S DRIVING ME CRAZY!
The Young Child with Attention Deficit Disorder
L. ADKINS & J. CADY
Information about typical behavior characteristics; offers suggestions on how to foster the development of appropriate behavior.
PE040AD - BOOK **$5.00**
PE040 - TAPE **$80.00**

SOMETIMES I GET ALL SCRIBBLY
Living with Attention-Deficit/Hyperactivity Disorder
MAUREEN BUSSE NEVILLE
Clinical, educational and emotional information from the point of view of a parent.
PE025AD **$18.00**

AUTISM

PARENT SURVIVAL MANUAL
A Guide to Crisis Resolution in Autism and Related Developmental Disorders
EDITED BY E. SCHOPLER
Includes many practical suggestions for dealing with the day-to-day challenges of life with a child who has autism.
PP045DB **$29.95**

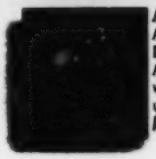
CHILDREN WITH AUTISM
A Parents' Guide
EDITED BY M.D. POWERS, PSY.D.
This book provides up-to-date information about autism, this comprehensive book will ease the fears and concerns of many parents struggling to understand and cope with their child's disorder.
WW017DB **$14.95**

WHEN SNOW TURNS TO RAIN
One Family's Struggle to Solve the Riddle of Autism
C.B. SCHAEFER
A father's moving account of his family's experience with autism, his son's perplexing disability.
WW023MB **$14.95**

AUTISM
Information and Resources for Parents, Families, and Professionals
R.L. SCHEIMAN & P. ZIARNIK
Written for parents and family members, in question-answer format, we attempt to answer common questions about autism.
PE043DB **$20.00**

ACTIVITIES FOR DEVELOPING PRE-SKILL CONCEPTS
In Children with Autism
T. FLOWERS
Each activity is designed to tell educators what they are doing, why they are doing it and what materials they will need to teach the activity. Adaptable for children of all levels.
PE025DB **$34.00**

CHILDRENS BOOKS



A CANE IN HER HAND
A.B. LITCHFIELD, ILLUSTRATED BY ELEANOR MILL
A great book to help children who are not physically disabled understand those who are.
AW111BL **$13.95**

HOWIE HELPS HIMSELF
J. FASSLER, PICTURES BY J.LASKER
Designed to help the child with a disability and the sibling identify with some of the joys, stresses and strains of a disability.
AW112PB **$13.95**

I'M DEAF AND IT'S OKAY
L. ASHLTINE, E. MUELLER & N.TAIT, PICTURES BY H.
How this little boy copes with the frustrations of deafness at play and at home.
AW134DF **$11.95**

MY BUDDY
A. OSOFSKY
Buddy is the best dog a boy could have. Fully illustrated, this book demonstrates the desires of the disabled to be independent.
HH000CB **$5.95**

JOEY AND SAM
I. KATE & E. RITVO,M.D.
A heartwarming storybook about autism, a family, and a brother's love.
BL000AM **$9.95**

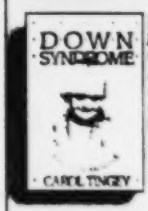
PRINCESS POOH
K.M. MULDOON, ILLUSTRATED BY L. SMITH
A sibling secretly dubs her sister 'Princess Pooh' because she sits on her 'throne with wheels' and gives orders. An honest look at some universal feelings.
AW110DB **$13.95**

BABY BOOK
For the developmentally challenged child
R. MATHEWS
A unique approach to the traditional "Baby Book" designed for children with developmental disabilities. Special sections for medical histories and Mom & Dad's feelings.
HH012200 **$25.00**

I'M THE BIG SISTER NOW
M. EMMERT, ILLUSTRATED BY G. OWENS
How the loving care of family and friends can influence and benefit the quality of life for mentally and physically disabled children.
AW113SI **$13.95**

DOWN SYNDROME

TEACHING THE INFANT WITH DOWN SYNDROME
A Guide for Parents and Professionals
M.J. KUMIN
The latest information on teaching activities for infants, resources for parents, medical facts about Down Syndrome and tips for parents on how best to help and enjoy their babies.
PE040DS **$29.00**



DOWN SYNDROME
A Resource Handbook
C. TINGEY, PH.D.,F.A.A.M.D.
A comprehensive introduction to Downs that answers medical questions and family living questions.
PE050DS **$24.00**

A PARENT'S GUIDE TO DOWNS SYNDROME
Toward a Brighter Future
S.M. PUESCHEL, M.D., PH.D., M.P.H.
Dr. Pueschel looks at important steps from infancy to adolescence. Readers are offered reassuring guidance and clear information about topics important to every family of a child with Down syndrome.
PP055DS **$29.00**

DOWN SYNDROME
Birth to Adulthood, Giving Families an Edge
J.E. RYNDERS, J.M. HORRBEN
This new book is an invaluable guide for parents of children with Down syndrome, as well as the professionals who help advance whole-family development.
LY120DS **$29.95**

COMMUNICATION SKILLS IN CHILDREN WITH DOWN SYNDROME
A Guide for Parents
L. KUMIN, PH.D.,CCC-SLP
Provides parents with a wealth of information about speech and language development in children with Down syndrome.
WW035DS **$14.95**

BEST COPY AVAILABLE

DOWN SYNDROME

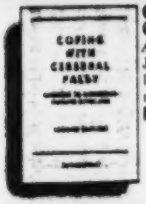
DOWN SYNDROME:
Living and Learning in the Community
EDITED BY L. NADEL & D. ROSENTHAL
This book will prove an invaluable tool for parents and health care professionals, enabling people with Down syndrome to cope with the problems they face and to participate fully in the community.
JWLLTDS $17.95

TEACHING READING TO CHILDREN WITH DOWN SYNDROME
A Guide for Parents and Teachers
P.L. OELWEIN
The only book on this subject, it describes a nationally known reading program that ensures success in presenting lessons which are imaginative and functional.
WRL29DS $16.95

BABIES WITH DOWN SYNDROME
A New Parents Guide
Second Edition
EDITED BY K. STRAY-GUNDERSEN
A newly revised complete and compassionate guide, written by doctors, nurses, educators, lawyers, and parents.
WRL54DS $15.95

MEDICAL & SURGICAL CARE FOR CHILDREN WITH DOWN SYNDROME
A Guide for Parents
EDITED BY D.C. VAN DYKE, M.D. ET AL
Designed to give parents a complete and easy-to-understand overview of specific medical conditions that are more common among children with Down Syndrome.
WRL33DS $14.95

CEREBRAL PALSY



COPING WITH CEREBRAL PALSY
Answers to Questions Parents Often Ask
J. SCHERZER
Provides carefully researched answers to more than 400 often asked questions.
PE053700 $26.00

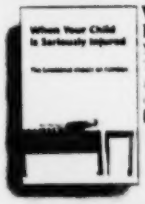
CHILDREN WITH CEREBRAL PALSY
A Parents' Guide
EDITED BY E. GERALIS
Essential reading for parents who want to learn about cerebral palsey and how it will affect their child and family.
WW012PD $14.95

I WISH...
Dreams & Realities of Parenting a Special Needs Child
K.D. MCANANEY
A book about conflict, courage and creative solutions.
CP074CP $8.95

CEREBRAL PALSY
A Complete Guide for Caregiving
F. MILLER, M.DD. &
S. BACHRACH, M.D.
This book offers sound professional advise and a caring commitment to do what's best for a child with Cerebral Palsy.
JHL50CP $35.95

INJURY

HEAD INJURY AND THE FAMILY
A Life and Living Perspective
A.E. DELL ORTO & P.W. POWER
Focuses on how the family can adjust and survive the trauma related to head injury, as well as become a partner in the treatment, rehabilitation, and adaptation process.
CRL0900 $29.95



WHEN YOUR CHILD IS SERIOUSLY INJURED
M. LASH, M.S.W.
Topics include preparing for hospital visits, reaction to loss, helping siblings, and coping.
EP005ML $4.50

WHEN YOUNG CHILDREN ARE INJURED
Families as caregivers in hospitals and at home
J. HALTIWANGER M.A.,ED M. & M. LASH, M.S.W.
A book about the family's role in caregiving when a young child is injured. Written for families with young children who have sustained debilitating injuries.
EP005ML $7.50

WHEN YOUR CHILD GOES TO SCHOOL AFTER AN INJURY
M. LASH, M.S.W.
Issues parents need to confront about their child's future schooling, health care and social needs.
EP006ML $7.50

MENTAL RETARDATION

DIFFERENCES IN COMMON
Straight Talk on Mental Retardation, Down Syndrome, and Life
M. TRAINER
Marilyn Trainer draws on her experience, with candor and humor, as a mother of a child with Down Syndrome, now in his twenties. A fresh outlook to the challenges, hopes and fears of family life.
WB009MR $14.95

CHILDREN WITH MENTAL RETARDATION
A Parents' Guide
EDITED BY R.SMITH, M.A., CCC-SLP
A complete and compassionate guide to everything parents need to know about raising their child and meeting her varied medical, therapeutic, and educational needs.
WB007MR $14.95

SIBLINGS

BROTHERS AND SISTERS
A Special Part of Exceptional Families - Second Edition
T.H. POWELL & P.A. GALLAGHER
This guide offers reliable research mingled with the perceptive wisdom of siblings of all ages to encourage a better understanding of the dynamics of family relationships.
PB07200 $21.00

IT ISN'T FAIR!
Siblings of Children with Disabilities
EDITED BY S.D. KLEIN & M.J. SCHLEIFER
Features chapters by parents, siblings and professionals.
EP001EP $14.95

SIBSHOPS
Workshops for Siblings of Children with Special Needs
D.J. MEYER P.F. VADASY
How to provide peer support and educational opportunities for sisters and brothers of children with special needs.
PB08600 $32.00

SIBLINGS OF CHILDREN WITH AUTISM
A Guide for Families
S.L. HARRIS, PH.D.
Understand sibling relationships, how autism affects them and what families can do to support their other children.
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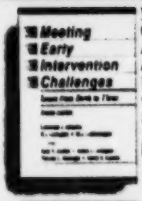

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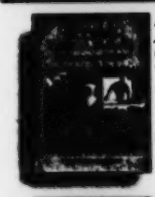

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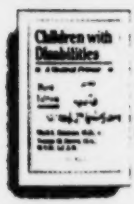

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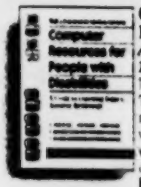

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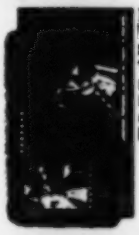

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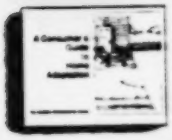

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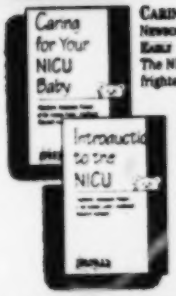

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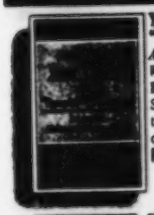

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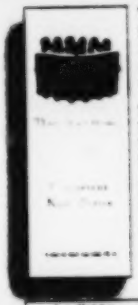

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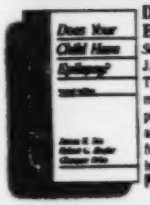

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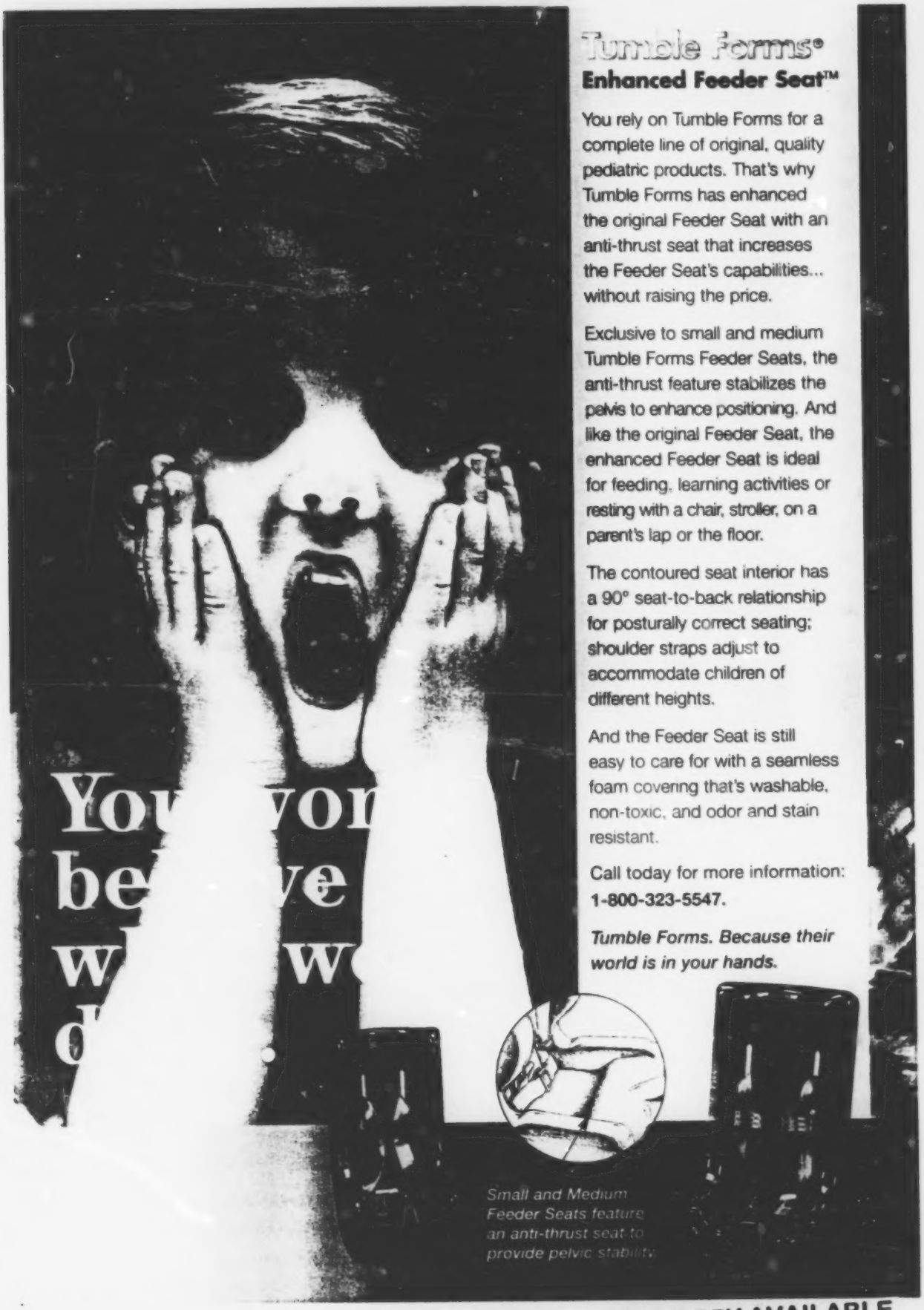
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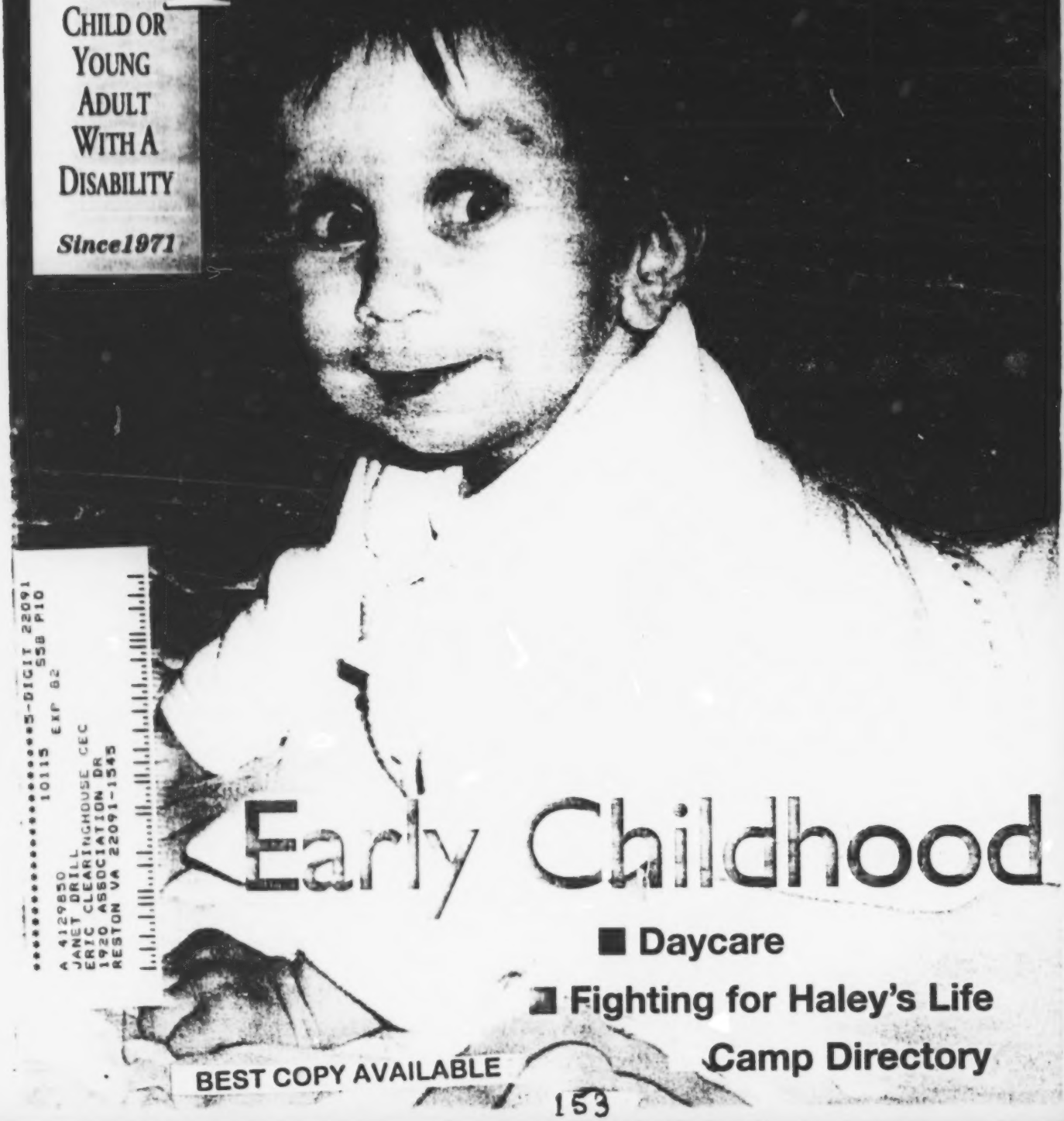
EXCEPTIONAL PARENT

The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971



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- Camp Directory

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You'll also receive a complimentary Ford Cellular Telephone* and Roadside Assistance* for the duration of the bumper-to-bumper limited warranty.

INFORMATION YOU NEED FOR INFORMED DECISIONS

The Ford Mobility Motoring Program also provides ...

- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- a video that shows adapted Ford and Lincoln-Mercury vehicles, and introduces you to people who are experiencing the independence of driving.
- sources of funding which may be able to provide assistance in addition to the amount you receive from the Mobility Motoring Program

PROGRAM PERIOD*

October 1, 1995 – September 30, 1996

When you're ready to adapt a new Ford or Lincoln-Mercury vehicle just call **1-800-952-2248** (for TDD users: **1-800-TDD-0312**). You'll discover that Mobility Motoring is your kind of reward!

*Customer is responsible for a 121-day minimum new activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.

Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance Plan. Vehicles covered by the Lincoln Commitment, Mercury Commitment or Red Carpet Lease plans may have additional benefits.

Ford
MOBILITY MOTORING PROGRAM

Circle #239

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Ford Lincoln Mercury Divisions

EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

FEBRUARY 1996 VOL. 26, ISSUE 2

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Cover: When Stephanie Agoratus was born with several serious kidney disorders, her mother, Lauren, was forced to rethink daycare options—"I had researched daycare options and chosen a provider while pregnant, but Stephanie's fragile medical condition had changed not only the rules, but also the game," Lauren says. Read about her search for daycare in "Help Wanted: Experience in Education or Health Care..."

Stephanie, 12 months in our cover photo, is now almost four years old. She lives in Allentown, New Jersey with her parents, Lauren and Steven. Although still considered "medically-fragile," Stephanie now enjoys frequent outings in the community and looks forward to attending preschool this year or in 1997.

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EDITOR'S DESK

Moving Mountains

When we read "Fighting for Haley's Life," Judy Engelman's story of her incredible efforts in what really can be called a do-or-die battle with a health insurance company, we knew we had the article that would be the centerpiece of this issue.

STANLEY D. KLEIN, PH.D.

Our exhilaration at the Engelmans' "victory" is tempered by sadness and anger that children and their loving parents—along with caring professionals—are all too often confronted by similar situations created by seemingly uncaring "systems." Year after year, throughout EXCEPTIONAL PARENT's 25-year history, our readers have faced similar challenges in their efforts to secure decent health care, education and other necessary services—and we have watched with awe as they moved mountains of resistance and lack of understanding. When Mrs. Engelman refers to herself and her husband as an "ordinary parents in an extraordinary situation," she speaks to the dedication and spirit of every parent and professional who reads our magazine.

As we begin another Presidential election year, we need to tell these stories and ask these questions of those who seek public office. At the same time, we will be off target if we focus our energies only on political leaders or insurance companies, because the purchasers of health insurance can also play a key role in changing the behavior of health insurance companies. Employers, the major purchasers of health insurance, want quality care for employees and their families because the short- and long-term costs of poor health care result in greater employee stress and lower productivity. They need to hear our stories, too.

Hopeful stories

Our *Readers Talk* stories about early intervention, along with Maria Gil de Lamadrid's article about the increasing access to daycare, provide reasons for guarded hopefulness. The families in these stories are reaping the benefits of changes brought about by other parents who refused to accept a status quo that ignored the needs of their children and families.

Within these stories is another essential lesson—that parents are experts about their own children, and that parental participation is critical to the success of any program, be it early intervention, daycare or home care for a child with special medical needs. In particular, readers' stories about early intervention programs—more positive than those in past years—illustrate professionals' growing appreciation of parental expertise and a willingness to collaborate with parents in making choices for their children. Parental participation can mean different things in different families and different situations. But in every case, parents need decent and dependable choices for themselves and for their children, choices that respect differing family and personal priorities.

Let's get away from it all!

Encouraged by readers' response to our tentative plan to celebrate EXCEPTIONAL PARENT's silver anniversary with our readers, we have started planning a family trip to Walt Disney World in late October 1996. To help us plan, we need to hear from readers about their interest in joining us and about the special needs of individual families that need to be addressed. Please send in the survey on page 52 right away if you want to join us! (Completion of the survey does not entail any obligation on your part.) We will keep you informed in the coming months.

I look forward to meeting many readers at the International Parent to Parent Conference in Albuquerque, New Mexico during the last weekend of March. By then, I hope to have more details about our trip to Orlando. For information about the Parent to Parent conference, write to Parents Reaching Out, P.O. Box 2640, Los Lunas, NM 87031, or call (800) 564-4772.

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EXCEPTIONAL PARENT

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For subscription and advertising information, see page 16

BPA

MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MARKUS SMITH
Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

For more information, contact:

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LETTERS

The Karate Couple

This is an open letter to Barry Atkinson ("The Karate Kid," October 1995):

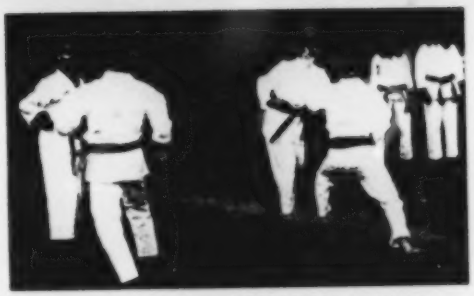
Hi Barry! We read your article in EXCEPTIONAL PARENT and wanted to let you know that we are very proud of you.

We have a special reason for writing to you. We know how hard you have to work as a student of karate. You see, we are a married couple, and we have both had cerebral palsy since birth. We didn't start taking karate until we were adults; now we have both earned black belts.

We understand that you feel nervous when you are the only one with a disability in a competition. We used to feel that way, too. But after doing karate so many times in front of people, we were able to forget our nervousness.

We are so glad we took karate. Like you, we took karate so we could learn to protect ourselves and also get some exercise. We now walk with more confidence. We pay closer attention to and are more aware of our surroundings. And we have met many new friends from other dojos (karate schools).

We even think karate has helped us in our volunteer work. We are "Family Friends," which means we volunteer to spend time with children who have disabilities. Because of our karate training, our movements come more naturally. This helps us to better protect the children with whom we play.



Don and Susan Bleich (left to right, facing camera) lead a backyard sparring session.

Keep up the good work, Barry. Although it may seem hard at times, we think karate will help you in all aspects of your life.

Don & Susan Bleich, California
"The Karate Couple"

Rhizotomy

Thank you for the article "Selective Dorsal Rhizotomy" (August 1995). The article, and the two family stories that accompanied it, took me back to September 1992, when our four-year-old daughter had her rhizotomy surgery. It was a very difficult time for us all. As much as we had prepared Christina and ourselves, none of us was truly prepared for the actual intensity of her recovery period.

Before the surgery, Christina's spasticity created a number of problems for her. Although she used a walker, every step required exhausting effort and concentration. Her legs scissored severely, and she walked on her tiptoes. When her daddy carried her on his shoulders, he would get neck cramps because her little legs were so tight. She was also unable to sit comfortably. We hoped the surgery would give her more ease of movement and make it easier for us to care for her.

Following surgery, Christina remained in the hospital "40 days and 40 nights"—we called it our "wilderness experience." I "lived" with her at the hospital and her daddy came to visit on weekends. The therapy was rigorous and intense—two to three times a day, five days a week. She hated it, and sometimes, she hated me; I know because she told me so. Many, many times I wondered why we had decided to do this to her. Those were the times I would call

EXCEPTIONAL PARENT

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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Convaid's buggies are the answer for moms and kids on the go. Long known for their patented folding design, they fold with all positioning adaptations in place. Moms can easily lift and store the buggies in a car trunk. Great for indoor or outdoor use.

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A choice of up to twenty options on Convaid's buggies includes a transparent detachable tray, made of unbreakable Lexan®, and a detachable canopy for shade and protection from the elements.

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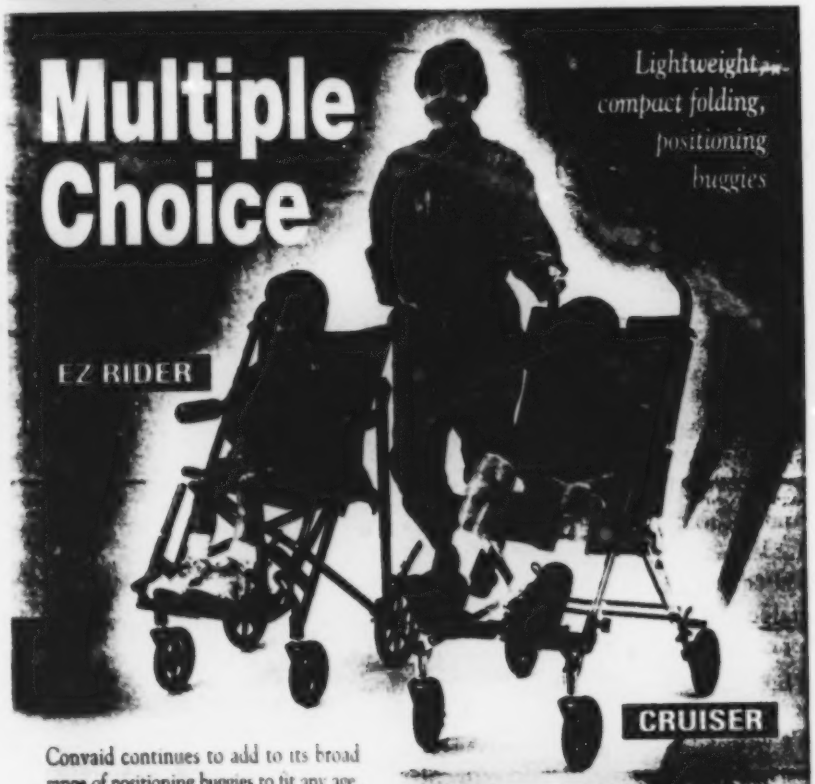
Now available, the Cruiser Transports, a new bus/van tie-down buggy line from Convaid, successfully crash tested at 30 MPH, 20g decel in a forward-facing configuration with up to 170 lb. dummy, using a Q-Straint (with positive lock) tie-down.

Good Looks, and Custom Comfort Make Kids Smile

Convaid's EZ Rider makes transport easy and fun with six colors, several sizes and extensive adjustability.



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Circle #155

LETTERS

continued from page 4

home crying. It was such hard work for her and so emotionally draining to watch her struggle.

When we finally came home, we continued the intense pace of therapy for a full year. I don't remember much about that year other than the four-times-a-week, 40-mile-round-trip physical therapy appointments! Several folks at the rehab center actually started asking if I had an "in basket" there!

Since that time, Christina has had other surgeries. In November 1993, she underwent a long surgical procedure to release her hamstrings and correct all the bone deformities that had been caused by her spasticity. Christina's most recent surgery was in December 1994, to remove pins that had been put into her hips during the November 1993 surgery.

In 1995, Christina finally had a year without any hospital stays. Her pink and purple wheelchair has been collecting dust in the garage for nearly a year. Last spring, as she was completing first grade, Christina informed us she was not going to take her walker to second grade; now it, too, collects dust. The walker comes out of the closet only at the end of an especially active school day or for one of those "shop-till-we-drop" mall trips.

You might ask, "But was it worth all that?"

My answer would be a resounding "Yes!" In spite of all the stresses our family has gone through, we are very grateful our daughter had the rhizotomy.

Should your child have a rhizotomy?

That decision should be based on what's important to your child and your family. What kind of supports do you have? Do you have positive and healthy outlets to relieve stress? Lots of questions need to be asked and answered when you are in the process of making a decision about corrective surgery for your child. For us, all the tears, the stress and the worries were well worth it!

J.F., Oregon

Cover to Cover

I just wanted to let you know how many people, like myself, truly enjoy

EXCEPTIONAL PARENT and read it from *cover to cover.*

After you printed a little story about my son, Kody, who has alobar holoprosencephaly, a very rare brain disorder (October 1995), I received calls and letters from families all over the United States. Even though my article had been edited down to three paragraphs and printed in *What's Happening* at the back of the magazine, it seemed like everybody read it!

Many times, doctors tell families that holoprosencephaly is a terminal disorder with severe mental and physical retardation. Our children are proving them wrong. That is why I believe it is important that we reach out to share our courage, strength and hope. I am volunteering to produce a newsletter and directory of families with children who have holoprosencephaly. Any family who would like to be included in a directory/newsletter may write to me (and also send a photo of your child if you'd like). Many thanks to EXCEPTIONAL PARENT for helping families get in touch with each other.

Brooke Rye
2050 Las Canoas Rd.
Santa Barbara, CA 93105

Understanding Enuresis

In the article "Understanding Enuresis" (August 1995), the discussion of treatments is not complete. While both antidiuretic hormone and the tricyclic antidepressants have a 70 percent rate of effectiveness, both have a relapse rate of more than 50 percent when discontinued. At that point, the child is back where he or she started and probably feels like a "failure."

Far more successful is the use of an inexpensive alarm system, the cost of which is frequently reimbursable by health insurance plans. Alarm systems are effective in more than 90 percent of children, and have a minimal relapse rate.

Bruce N. Bogart, M.D.
Schneider Children's Hospital
New Hyde Park, New York

EDITOR'S NOTE: The article "Understanding Enuresis" was adapted from materials provided by the Simon Foundation for Continence (P.O. Box 815, Wilmette, IL 60091; 800/237-4666). Letters received in response to that article have been forwarded to the Simon Foundation.

Information and Support

I absolutely love your magazine. I anxiously await its arrival and immediately read it from cover to cover. It is a great source of information and support. Thank you so much for its publication. I do wish friends and family were able to find it on the newsstands. I'm sure it would do well.

J.C., Kentucky

EDITOR'S NOTE: Barnes and Nobles Superstores will be carrying monthly issues of EXCEPTIONAL PARENT in 1996.

Homeschooling

Please cancel my subscription immediately! As a homeschooling parent, I have been very patient reading your magazine. However, I feel that my subscription is a waste of money because you promote a system of education that does not work for my child.

Your underlying message seems to be that parents are not capable of raising a child with disabilities without direction from a cadre of experts. I believe, however, that parents know their own child's needs better than anyone else and are often the most capable of directing their child's education.

Do your readers a service by including an objective, informative article on

continued on page 9

Tell us about...

... what EXCEPTIONAL PARENT has meant to you and your family.

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in our special 25th anniversary issue (June 1996).*

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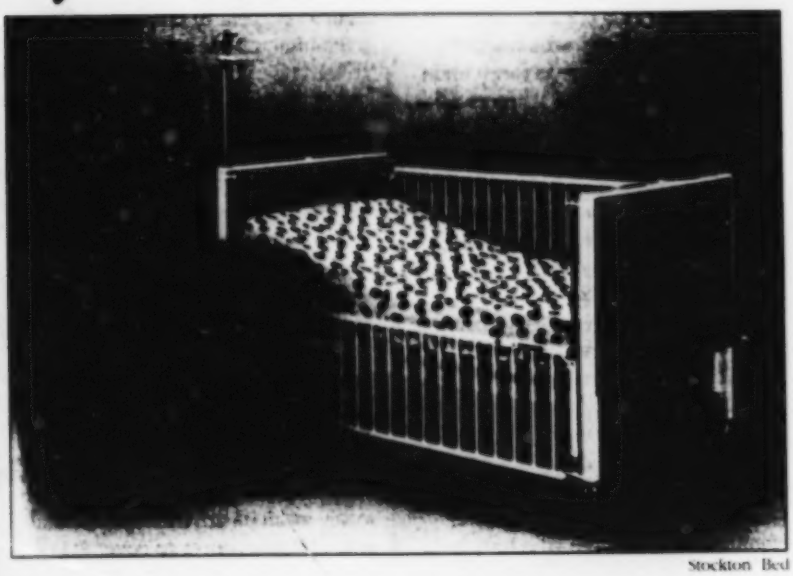

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T. Berry Brazelton, M.D.
Clinical Professor Emeritus of Pediatrics, Harvard Medical School

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James A. Autry
Former President, The Magazine Group (Better Homes and Gardens), Meredith Publishing, Des Moines, Iowa

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Mental Retardation
Autism, Epilepsy
Learning Disabilities
Perceptual Disabilities
Hearing Impairments
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Emotional Problems
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EXCEPTIONAL PARENT'S mission is to

PROVIDE practical guidance and support for parents, educators and professionals caring for children and young adults with disabilities and special health care needs.

INFORM parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities and their families

SERVE as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators

FOCUS on the child first, the disability second

read it monthly.

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the National Challenged Homeschoolers Associated Network (NATHHAN) in next year's education issue. Let your readers know they have other options besides the system.

K.S., Montana

EDITOR'S NOTE: For 25 years, EXCEPTIONAL PARENT has been dedicated to recognizing and supporting the expertise of parents, and promoting the need for parents and professionals to collaborate respectfully. We recognize that each child has individual needs and have never promoted a one-size-fits-all approach to education, health care or any other aspect of a child's life. Rather, we have tried to advocate for a variety of good choices for both parents and children, while making every effort to provide a forum for sharing the sometimes differing viewpoints of both parents and caring professionals.

Homeschooling may be the best educational choice for some families; we know of several readers who homeschool their children, and we would certainly be open to publishing an article on the subject. We know that NATHHAN (5283 Alpine Rd. SE, Olalla, WA 98359; 206/857-4257, voice/fax) is an excellent resource for many homeschoolers who have children with disabilities, however, the organization's emphasis on Christian beliefs and teachings may make it a less useful resource for families who are homeschooling for other than religious reasons.

Corrections

- In September 1995, an incorrect address was listed for the Adaptive Environments Center mentioned in a sidebar to the article "Your Child's Bathroom." The correct address is Adaptive Environments Center, 374 Congress St., Ste. 301, Boston, MA 02210. We apologize for any inconvenience.
- In November 1995, the toll-free phone number for the MOVE International Foundation given in the special advertising section on page 56 was incorrect. The correct number is (800) 397-MOVE. We apologize for any inconvenience.
- In November 1995, one of the boys pictured on the cover was identified as Justin Edwards. His name is Justin Savage. EXCEPTIONAL PARENT regrets the error.
- In November 1995, a letter in *Respond* listed an incorrect toll-free number for Medic Alert. The correct number is (800) 344-3226. We apologize for any inconvenience.

Clarifications

- The Flotation Healthcare Foundation (mentioned in a letter in *Respond*, October 1995), has asked us to inform readers that requests for flotation systems (waterbeds) will be processed more quickly if they include a prescription or recommendation by a physician or other health care professional and a statement from a social counselor regarding the ability of the prospective recipient to pay for such a system. Both prescription and statement should appear on the letterheads of the professionals supporting the request.
- EXCEPTIONAL PARENT would like to acknowledge the Provincial IODE Genetics Resource Centre (Children's Hospital of Western Ontario, 800 Commissioners Rd. E., London, ON, Canada, N6C 2V5, 519/685-8140) for their help in gathering Canadian resources for the 1996 Annual Resource Guide. The Centre invites readers to visit their Internet web page (http://www.vichosp.london.on.ca/medaff/medgenetics/support.html), which contains a searchable directory of Canadian genetic support groups.

Circle #271

SEARCH

Familial Paroxysmal Rhabdomyolysis

We are seeking information on familial paroxysmal rhabdomyolysis, a disease involving skeletal muscle degeneration, which has attacked Claire, our three-year-old daughter, twice in the last 10 months. Both cases were life-threatening and came on rapidly after normal flu-like symptoms. She went from being slightly sick to severely ill within a few hours. Both times, the disease attacked Claire's muscles to the point where she could neither walk nor move any of her extremities.

In 1992, our four-year-old daughter died suddenly as a result of this disease. With some further understanding, we hope to keep Claire healthy. If you can share any information on this rare condition, please respond immediately.

R.B. & M.J.B., Florida

Duplication 3q

My four-year-old son, Isaac, has been diagnosed with duplication 3q (duplication of the long arm of the third chromosome). He has seizures (mixed type) that are almost fully controlled with Klonopin and Felbatol. Isaac has a visual impairment and developmental delays in all areas. These problems are all consistent with his hypomyelinization of the brain and optic nerves. ("Hypomyelinization" means he has insufficient myelin, the fatty covering that insulates the nerve fibers of the spinal cord and brain. Insufficient myelin causes a breakdown in the transmission of body signals to and from the nerves.)

Duplication 3q usually involves serious heart and kidney defects, but, so far, Isaac has only a mild pulmonic stenosis (constriction of the pulmonary artery). Because his physical problems are mild, Isaac has outlived most reported cases of duplication 3q, so doctors have little to go on in making a prognosis.

Isaac's developmental delays are quite severe. On most scales, he tests at the eight- to 10-month level, higher in language and lower in social skills. He is very active, however, and moves around by combat crawling, scooting on his rear or using a ring walker. He is good-natured, sociable and curious. He has just begun to be amused by unusual or odd events and situations. He needs constant care and supervision.

I am very interested in hearing from other parents of children with duplication 3q, or from parents of similar children, regardless of diagnosis. I am particularly interested in hearing from people who are dealing with difficulties in feeding (my son still prefers commercial baby food and yogurt), sleeping (Isaac's sleep patterns are fragile, frequently regressing to a series of widely spaced naps with no prolonged sleep periods), keeping a child occupied and providing social experiences.

L.T., Michigan

Down Syndrome & Acute Lymphoblastic Leukemia

My four-year-old son, Christopher, has Down syndrome and is also in remission from acute lymphoblastic leukemia. I would like to be in touch with other families who have children with Down syndrome and leukemia. I do know of one other case besides Christopher, but that child had a different type of leukemia.

C.C., Illinois

Gender-Ambiguity and Craniosynostosis

My two-and-a-half-year-old daughter, Leah, was born one month prematurely and was small for gestational age. She has a number of anomalies, but the "major" ones are ambiguous gender (surgery done at four months with more at puberty); lambdoidal craniosynostosis, meaning some of the bones in the back of her skull fused prematurely leaving insufficient room for brain growth (corrective surgery done at five months followed by a year of wearing special skull caps); "rocker-bottom" feet and moderate to severe global developmental delays, especially with regard to speech and age-appropriate eating (she is still bottle-fed). Leah remains quite small for her age—around the third percentile.

Leah has been evaluated for many syndromes, but, so far, all tests have been negative or inconclusive. I have already done extensive searching and, although I've found some wonderful friends, I have yet to locate a child "like" my Leah. I would especially like to connect with other parents of children who were born with gender-ambiguity, as well as professionals who can offer further information on this subject. I would also be happy if my experiences—especially regarding gender-ambiguity and the use of skull caps—could be helpful to others. I am open to anyone who would like to contact me!

D.G., South Dakota

No Father's Voice

I have a five-year-old daughter and a two-year-old son with cerebral palsy. I work full time, though I need to take time off each week for therapy or doctor's appointments. I am married, but somehow, all the household and child care responsibilities have become mine, and mine alone.

My husband owns his own business. He works day and night and Saturdays, too. On weeknights, he usually arrives home around 9 p.m., just as I am tucking the kids into bed. I have griped and complained and cried about him working so late when I need help at home, but nothing ever changes. He has never given our son a bath, and rarely has he fed him. He has never done exercises with our son, nor tried to help him play with a toy. Once, when I asked him to place our son in his standing frame, he complained terribly. He has never offered to take our son to therapy or to a doctor's appointment. He has never

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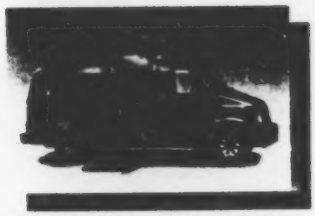
B R A U N



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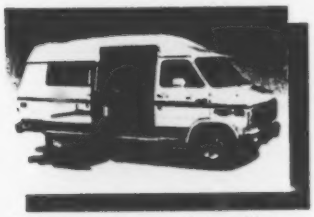

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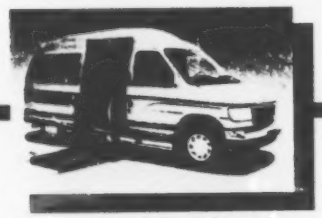

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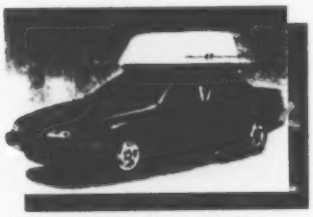

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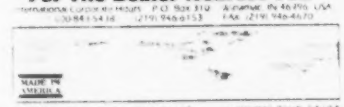

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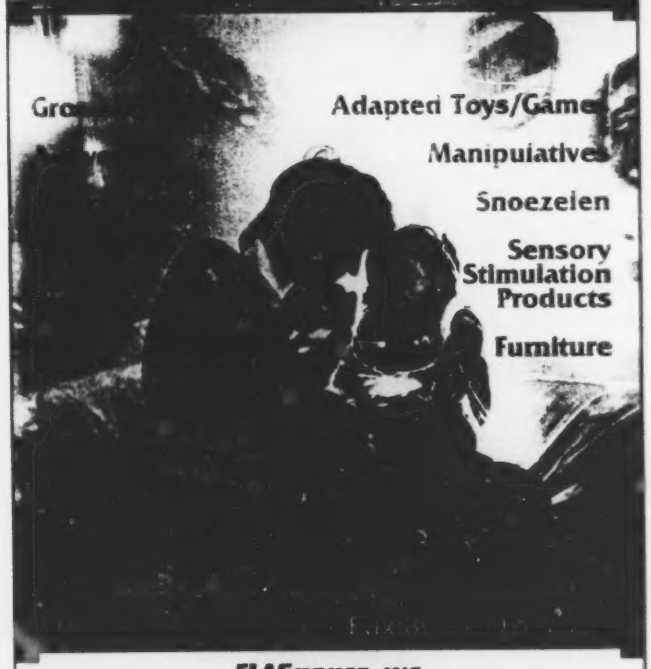

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Circle #270

SEARCH

continued from page 12

been interested in reading EXCEPTIONAL PARENT magazine or any of the many books on disability I have purchased. I read the *Fathers' Voices* column each month and wish we had a "father's voice" in our home.

I don't want to make him sound like an awful person—he really isn't. I know he loves all of us very much. Maybe he avoids us so he doesn't have to accept our son's disability and deal with it. But his avoidance is not fair to me; I am tired and I have no help.

I realize we probably need either family or marriage counseling. But I don't know how to get started, or how I would convince my husband to go along with me. And this may sound strange, but I feel like going to counseling would just prove we are failures who can't handle our own problems! I would love to hear from any parent who has been in this situation. Tell me how you've dealt with it.

T.W., Iowa

Undiagnosed

Our son, Clay, now one year old, was born at 38 weeks gestation with several anomalies including hypospadias (a condition in which the urethral canal opens on the undersurface of the penis, before reaching the tip of the penis), sacral dimple (small indentation at the tailbone), brachycephalic skull (a relatively short head) and bilateral preauricular pits (depressions just in front of each ear). He also has microcephaly (a small head for his age) and a very flattened nasal bridge. He is unable to sit, crawl, walk or stand.

At eight months of age, Clay had an hour-long seizure and was hospitalized for nine days. Although many tests were run, the doctors were unable to find any reason for the seizure. Clay has had a chromosomal study, which has come back normal; a metabolic study is now being done.

I would like to hear from any other parents who may also have a "mystery baby." I would like to know how they went about getting answers.

R.W., Florida

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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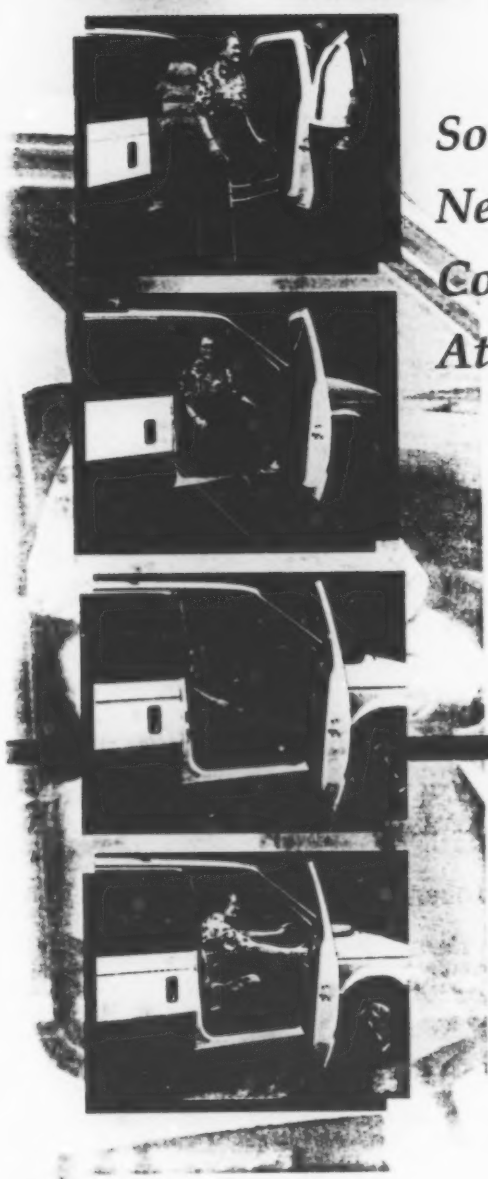
Fax (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

B R A U N



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Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle rebates are also listed in this comprehensive booklet. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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B-90-214

RESPOND

Undiagnosed

D.C. (October 1995) was seeking a diagnosis for her three-year-old son, David, who has hypotonia (low muscle tone), scoliosis (curvature of the spine), cataracts and nystagamus (rapid, involuntary eye movements). Recently, David has stopped eating solid foods. His gross motor skills seem to be regressing. Muscle biopsies and other tests have revealed no diagnosable problems.

Some of David's symptoms are similar to those of our granddaughter. She also has hypotonia, scoliosis and feeding problems. She had several eye problems stemming from a lack of tears. She also had additional symptoms you do not mention, but neither did we realize their presence at the time; these symptoms included lowered sensitivity to pain and brief but frequent episodes of elevated body temperature.

Although she was examined by the best pediatricians and other specialists, we, too, were unable to find the cause of her symptoms. By chance, we met a radiologist who knew about a rare genetic disorder called dysautonomia. He thought her symptoms might indicate this disorder and suggested that we contact the Dysautonomia Foundation (20 E. 46th St., Rm. 302, New York, NY 10017; 212/949-6644). The simplest of tests, a drop of histamine delivered subcutaneously (under the skin), confirmed the diagnosis.

I do hope you find the cause for your son's problems. The Dysautonomia Foundation will be very helpful should your child need their services. I wish the best for your son, whatever the cause of his problems.

M.L., New York

EDITOR'S NOTE: Canadian readers can contact the Canadian Dysautonomia Foundation, 343 Clarke Ave. W, Ste. 1103, Thornhill, ON L4J 7K5; (905) 882-7725.

■ Hypotonia, scoliosis, cataracts and nystagamus are primary symptoms of Lowe syndrome, an inherited metabolic disorder that occurs only in males. Boys with Lowe syndrome are usually underweight because they are not very motivated to eat. They are normally happy and loving children, but sometimes have certain behavior problems. They may also develop renal tubular acidosis, a disorder in which the kidneys fail to secrete enough hydrogen or to re-absorb enough bicarbonate. This condition can lead to further medical problems.

For more information about Lowe syndrome, contact

continued from page 18

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Circle #196

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the Lowe Syndrome Support Association, 222 Lincoln St., West Lafayette, IN 47906; (317) 743-3634; kayeuulsa@aol.com.

D.N., Illinois

Congenital Muscular Dystrophy

C.D. (October 1995) has a four-year-old daughter, Olivia, who has been diagnosed with congenital muscular dystrophy. Since beginning physical therapy at the age of 18 months, Olivia has started to crawl short distances, scoot on her rear end and climb on and over low objects. Olivia's doctors have been unable to predict whether her motor skills will continue to progress or will eventually start to regress. Nor have they been able to predict C.D.'s chances of having additional children with the same condition. C.D. hoped other parents could provide some answers.

My two-and-a-half-year-old identical twin sons, Jordan and Andrew, were diagnosed with congenital muscular dystrophy at the age of 10 months. We had known something was wrong because they were extremely weak and did not achieve appropriate motor milestones. We also had an older child, Joshua, whose development we could compare to theirs.

We are lucky to have a fantastic neurologist, who has helped us understand not only the diagnosis, but the somewhat hazy prognosis as well. The Muscular Dystrophy Association has answered our many questions and provided special clinics and doctors to help us deal with this disease.

Jordan and Andrew have been in occupational, physical and speech therapy since they were a year old and continue to make steady progress. Jordan can walk on his own but cannot run, climb stairs or lift his legs enough to climb up onto furniture. His upper body seems weak and, recently, has been "collapsing" without warning when he's walking; also, his legs seem to buckle more easily than before.

We don't believe Andrew will ever stand or walk. He is in a wheelchair when we go places, but at home he can keep up with Jordan by scooting on his bottom. He also has more significant medical problems than Jordan, including severe congenital scoliosis, a heart defect and feeding problems (he receives night feeds with a g-tube and pump because he eats little by mouth).

The many doctors and neurologists we have seen are not exactly optimistic about the future, however, they admit they do not know much about congenital muscular dystrophy. Because of Andrew's more significant medical problems, they believe his life span will be considerably less than normal. They think Jordan has a better chance for a longer life span, but they are not comfortable giving me a more specific prognosis. They say it all depends on whether his muscles are generating faster than they are dying.

We are currently expecting our fourth child, a girl. We have not undergone any genetic testing, nor have we been pressured to do so. If she is affected, we will deal with it. We still plan on having more children in the future.

Our lives have been totally blessed by each of our children. Our priorities have changed; our twin sons have helped us put so many things into perspective.

K.K., Texas

■ Our 11-year-old son, Roger, also has congenital muscular dystrophy. No one can tell us what tomorrow will bring, but I can tell you that what Roger lacks in strength, he more than makes up for in determination!

As a young child, Roger had a manual wheelchair for school and a small three-wheeled power scooter for use at home. However, he has always preferred to scoot around on the floor at home since he can reach things better that way. He now uses a power chair because he never developed enough strength to propel himself in the manual chair and, in middle school, the children have to change classes.

Roger is in the sixth grade and is always on the honor roll. He has a very outgoing personality and lots of friends. Roger feeds himself, but it takes a lot longer for him to eat. He also can use the bathroom independently, but again, it takes extra time. He is starting to talk about dating, going to college and doing all the other things his older brother and sister have done.

We are currently remodeling our house so he can achieve full independence here. We have installed a ramp in the garage so he can get in and out of the house by himself, and we have modified one bathroom by putting in a transfer bench and shower with temperature-control sensors. We continue to search for other parents with similar children to see what we can learn from each other.

R.H. & J.H., Indiana

■ My five-year-old son, Brian, was diagnosed with congenital muscular dystrophy at 20 months of age. He is the only one of our six children to have this condition. Brian seemed to be a normal infant except for a dislocated hip, however, by the time he was four months old, his motor skills were beginning to lag. He did not roll over, and he did not hold his head up when placed on his stomach.

With physical therapy, Brian started to walk at 17 months of age. He still cannot run, jump or climb stairs; however, he walks well on a level surface and can get around our home independently. Last year, he got a motorized scooter, which gives him increased mobility outside the home. He is a very bright child who attends a public school kindergarten class. All the neurologists who have evaluated Brian tell us that we should not expect Brian's physical condition to deteriorate over time; in fact, he may improve.

Congenital muscular dystrophy is an uncommon type of muscular dystrophy, and Brian seems to have a very mild form of the disease compared to descriptions in the medical literature. I think this is an example of how diseases come into the medical literature with an "identification bias." This means that the most severe cases of a disorder are identified and described first. Only later are milder cases recognized and diagnosed. Because of this, descriptions in the medical literature may not reflect the full spectrum of a disorder's presentation, and especially, may not describe the milder forms.

B.C., Missouri

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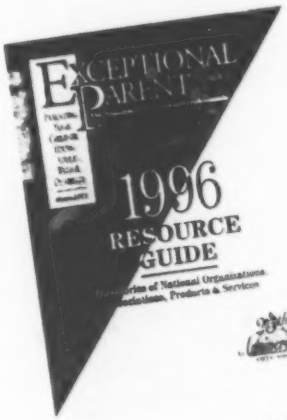

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25th Anniversary 1971-1996

The View From My Window

by Courtney Lai-Hing

I glance up from the computer screen and look out the window. I have been working at home. My son is here, too. He has had some problems at school, and his teachers decided he should have a "time out" at home. So here I am—staring out the window and taking my own "time out" from my work.

We live in a suburb of Montreal, where the school board has committed itself to integrating students with disabilities into regular classrooms with children of the same age. So this year, when my son turned 13, it was a birthday that signaled the beginning of high school. Intellectually, David understood the change that was coming, but he still felt the emotional pull of his old, familiar elementary school. All summer long, he kept asking, "Why do I have to change schools?"

We gave him the usual answers: You have graduated from elementary school and it's time to move on; you will be learning new and exciting things in high school; some of your friends will be there, too. He finally seemed to accept these explanations and, equipped with a "teenager" backpack and a new pair of running shoes, he headed toward the bus on the first day of school.

The first week passed uneventfully. David seemed to be adjusting well. We had not seen or heard anything to indicate otherwise. My wife and I breathed a sigh of relief.

The following week, we received the telephone call from school. There had been some problems. The teachers had held off calling; they'd wanted to wait and see if things would improve. But nothing had changed. Perhaps David should spend a few days at home.

By the time I hung up, I was experiencing that sinking feeling one gets after hearing bad news. What should we do next? How can we help our son adjust?

Courtney and David Lai-Hing relax after a delicious meal on Canadian Thanksgiving (celebrated the second Monday of October).

These are the times when I feel frustrated and angry. I have long since accepted that God has allowed me to have a child with disabilities: I no longer ask Him why. Instead I ask myself how I can possibly meet all my son's needs. How can I create an environment that gives him the confidence to participate to the best of his abilities without feeling angry and frustrated? How can I overcome my own frustration so I can work on finding ways to help him? How do I get him out of bed in the morning when he would rather hide under the covers? How can I help him accept himself?

A line from one of Reverend John Donne's famous meditations runs through my thoughts and startles me with its intensity—"No man is an island, entire of itself; every man is a piece of the continent, a part of the main." It makes me think of all the other parents who face the same challenges. I am reminded of why my wife and I became members of our local parent support group, the West Island Association for the Intellectually Handicapped. We knew we needed others who could share our pain, our failures, our successes and our joys. In the midst of our soul-searching and self-recriminations, we were able to reach out to others. We found friendship and understanding.

continued on page 22

David (right) celebrated his thirteenth birthday with a few buddies.

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Circle #267

Cornflakes and love: David and his mom, Elaine, enjoy an early morning hug.

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I now know what I must do for my son. I must continue to love him unconditionally. I must help him through the tough times. I must be there when he needs an advocate. I must share his pain. I must help him deal with his anger and frustration; in doing so, I will reach down deep inside myself and deal with my own emotions.

The wind has picked up and the blue spruce is swaying back and forth in a gentle movement reminiscent of an old rocking chair. One by one, the leaves from the maple are blown high into the air. They drift slowly into the neighbor's yard.

Winter is coming. Soon the ground will be covered with leaves. We will hear the sound of laughter as costumed children drift from house to house on Halloween night. I will be there with my son. He plans to go as Batman; we already have his costume and loot bag. We will enjoy trick-or-treating and share the candy he collects. I turn away from the window. It is time for me to get back to work. **EP**

Courtney Lai-Hing lives in Point-Claire, Quebec, a suburb of Montreal, Canada, with his wife, Elaine and son, David, 13. Courtney and Elaine also have two older children, a daughter, 22, and son, 24. Courtney, a member of the Institute for Electrical and Electronic Engineers, works as a self-employed consultant. He is also on the board of directors of the West Island Association for the Intellectually Handicapped. Elaine works as an integration aide with the Lakeshore School Board. David, who has cerebral palsy, attends regular classes at a local high school with the help of an integration aide.

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

Mostly For Parents

Books and Videos About Living With Seizures

Children with Epilepsy: A Parents Guide

Edited by Helen Reisner
Woodbine House, Inc., 1988

Edited by the mother of a child with epilepsy, this book is designed to help parents understand the nature of epilepsy in children and to familiarize them with therapy, coping skills and some of the special issues that arise when a child has severe seizures. Contributors to the book include parents and professionals.

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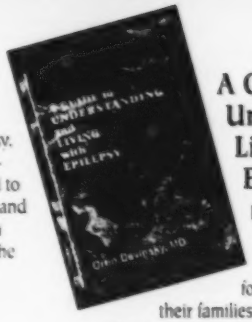

A Guide to Understanding and Living with Epilepsy

By Orrin Devinsky, MD
F.A. Davis Company, 1994

Easy-to-understand resource for people with epilepsy and their families. Covers a wide range of medical, social and legal issues. Topics include explanation of seizures and epilepsy; information about medication, side effects and risks; and getting the best medical care.

Catalog # 228GUL
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Does Your Child Have Epilepsy?

By James E. Ian, MD, FRCP, Robert G. Ziegler, MD and Giuseppe Erba, MD University Park Press, 1983

Establishes "Ten Basic Rules" for parents of children with epilepsy. It addresses the initial fears parents have: Is my child going to die? Will he be retarded? How did he get epilepsy? Is epilepsy inherited? Provides information on how to manage your child's condition, how to work with physicians to obtain appropriate medical care and how to cope with changes that occur as both the child and family mature.

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Provides an explanation of seizure disorders in everyday language. Dispels many misconceptions about epilepsy with medically accurate information; describes what happens in the brain during a seizure, and explains why different people experience different symptoms.

Actual seizure footage is used. Doctors explain how they use family and patient histories, EEG's and other tests to look for causes and accurately diagnose epilepsy. A Family Video Library presentation. (1990)

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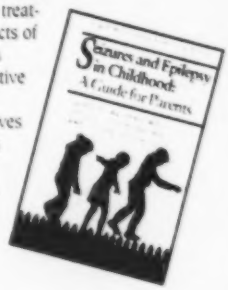
Seizures & Epilepsy in Childhood: A Guide for Parents

By John M. Freeman, MD, Eileen P.G. Vining, MD, and Diana L. Pillas
The Johns Hopkins University Press, 1990

Written for parents who want to understand as much as possible about the causes, mechanisms, treatment and social aspects of epilepsy. Encourages parents to become active partners in their children's care and gives them the background information (and vocabulary) to do so.



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Familiar Faces

Hiker **Lindsay Jordan Walters,** 11, of Indian Rocks Beach, Florida, pauses for a break beside a babbling brook. According to her mother, Lindsay is a real outdoors kid—when not hiking, she enjoys riding her bike, rollerblading and playing golf. She also enjoys artwork and playing with her brother, Kevin, 2, who has Down syndrome. Lindsay, a fifth grader at the Mildred Helms school in Largo, has attention deficit hyperactivity disorder (ADHD).

"Way to go!" Six-year-old Porsche Lee Gordan gives her grandmother, **Mary Lou Voorhees,** a congratulatory pat on the back. Looking on is Porsche's younger brother, **Michael,** 3. Mary Lou, who had just received her Associate of Arts degree in special education, describes Porsche as her inspiration. Porsche, now 9, lives in Arlington, Texas. She has spina bifida.

Tobias James Carroll, 6, of Van Nuys, California, takes a break from his busy schedule to smile for the camera. Toby has developmental disabilities and mild hypotonia. He also has quite a personality! Toby loves the water and has taught himself how to swim. His mom, Wendy, writes that she "can't wait to get him into the Special Olympics aquatic program."

Birthday girl **Melissa Rodriguez,** 7, giggles as her mom, **Rosy Ramos,** helps her blow out the candles. Melissa's favorite part of celebrating her birthday is the Happy Birthday song. "It is amazing how a simple song can brighten a little girl's face," notes her mother. Melissa, who lives in Miami, Florida, is an avid swimmer and loves anything to do with the water. She is diagnosed with agnesis of the corpus callosum.

"I've got the keys, now where should we go?" **Wesley Alan Harville,** 3, and his brother **Justin,** 6, take a little break by the side of the road. The two enjoy spending time together, especially at their favorite park. "Wesley tries to do everything his brother does!" writes his mom, Donna. "He is a very happy guy and we are blessed to have them both." Wesley, who has a shunt for hydrocephalus, mild cerebral palsy and a seizure disorder, lives with his family in Dayton, Ohio.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

On more than one occasion, Mead has been able to combine his love of music and sports. Here, he sings the National Anthem at the Georgia State Games in 1993. He also sang at the closing ceremonies of the 1988 Paralympics in Barcelona, Spain, where he captured a silver medal in the long jump with a jump of 4.62 meters (15 feet, 2 inches).

Al Mead

Jumping into the record books

Al Mead, 37, a member of the U.S. Paralympics team, is currently training for the 1996 games in Atlanta, Georgia, where he will compete in the long jump, high jump and pentathlon. Mead, an above-knee amputee, also serves on the board of directors for the Atlanta Paralympic Organizing Committee and on President Clinton's Council on Physical Fitness and Sports.

Out in the community, Mead is greeted enthusiastically—and with more than a little awe—by youngsters who recognize him from one of his many disability-awareness presentations in local schools. "I always give the kids demonstrations of how my prosthetic leg works," he explains. "I even jump up to the basketball hoop and grab the rim. They are always amazed."

Mead is a partner in an executive search firm in Atlanta. He also serves as the music director at Lincoln Baptist Church in College Park, Georgia. He lives with his wife of 10 years, Rochelle, and their daughters, Karen Ashley, 7, and Monique, 4. The following was adapted from an interview between Mead and EXCEPTIONAL PARENT *intern Ellen Bullock.*

I grew up on Chicago's south side with my mom, Gwen, my dad, Albert Mead Jr.—I'm actually Albert III—and two younger siblings, Jenny and Steve. My family was very close. We all went to church together, and we always ate dinner together. We did everything as a family. I'm sure this closeness played a big part in easing any pain I had growing up with an artificial leg.

The events leading up to the amputation of my leg probably began when I stepped on a nail: my mom brought me to the doctor, who just sent me back home. Then, a few months later, I was shooting some hoops with my godmother's son, and I fell down on my back. For some reason, this started my foot hurting all over again.

I was nine years old. I remember the day clearly because it was the day of the Martin Luther King Jr. funeral in April 1968. When I got to my godmother's home and explained what had happened, I remember the attention was divided between me and the televised funeral.

My godmother thought I had sprained something. She rubbed my leg down, and I soaked my foot at home. But a few days later, when it continued to hurt, my uncle, a medical technician at a local hospital, did a few informal procedures to assess the location of my pain. He was the one who noticed that most of my foot was numb. Convinced something was really wrong, he brought me to the hospital.

The doctors agreed something was seriously wrong and kept me in the hospital for further examination and treatment. Eventually, they had to amputate my foot. A few days later, they determined that the infection was worse than originally thought. So they amputated again, just below the knee. Then, still later, they amputated my leg just above the knee. So I actually had three amputations.

When my mom first told me they were going to amputate, I wasn't particularly upset, probably because I didn't really understand what I was facing. I remember my mother crying, and I told her, "Don't cry, Mom. My leg's gonna grow back, isn't it?"

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Al was an active nine-year-old when his left leg was amputated above the knee. In this third-grade class picture, taken a year earlier, he's the Cub Scout at the far right in the third row.

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Time of change

It wasn't until the end of my five-week hospital stay, when they started training me to roll a wheelchair and walk on crutches, that I realized things were going to be different. It really hit me when I came home so obviously different from the day I'd left.

I had to stay home from school until I got my first prosthetic leg. While all the other kids were at school and my parents were at work, I spent a lot of time on the corner of our block. I would just sit there, with my crutches over my lap, watching the cars go by. I must have looked pretty sad because the cars started slowing down. Some of them stopped, and people got out and gave me money.

I decided right away that this was not the way I wanted to be seen—a poor little crippled kid feeling sorry for himself. I knew I had to start turning that stereotype around.

Back in the game

I started learning to ride a bike soon thereafter. I just climbed on and started practicing. My mom says I almost gave her a heart attack the first time she saw me trying to ride my bike with one leg. She didn't know whether to yell at me to get off the bike or just let me go and hope for the best. She swallowed her fear and let me continue to ride. I fell on my face a few times, but soon I was able to ride with one leg.

Proud Dad Al Mead, shown here with daughter Monique, describes his wife and children as "the best family in the world."

Once fitted with my first prosthesis, my next challenge was getting back into our neighborhood games of "alley football." The kids were reluctant to include me, because they were afraid of being blamed if I got hurt. I eventually convinced them to let me play and it didn't take me long to get a good feel for a hop-skipping type of run. When I finally got my hands on the ball, I headed for the goal line at the end of the alley. At that moment, the bottom part of my leg fell off.

There was my foot on the ground, and I had the football, and nobody knew what to do. I said, "Hey, don't worry, guys. I'm OK. Just let me get this touchdown, then I'll go get my foot fixed."

I have no doubt that my participation in sports was the rehabilitation vehicle that got me back into the mainstream of society. Baseball was my first love; I played on a community team, eventually becoming an all-star catcher. I even learned to steal bases. I played hockey in the winter and I started to play basketball in seventh grade. I tried out for the basketball team in high school, but even though I made the cut, the coaches decided against letting me play because they were worried about the possibility of a lawsuit if I got injured. But I played intramural basketball, and our team won the school tournament. That made me feel a bit better.

It wasn't so much that I loved sports, but that I loved the challenge of letting everybody know that I could hang with them and be just as good, in spite of the additional challenge I faced. My biggest struggle was with a series of prosthetic legs that just couldn't keep up with me. In those days, prosthetics were not made to accommodate sports activities or active kids. I would bail out of swings like everybody else, or I'd climb a fence and jump off, then I'd walk home and there would be ball bearings all over the floor. Not a week passed that I didn't have to bring my leg in for some sort of repair.

Getting into track and field

After high school, I moved to Atlanta, Georgia to attend Morehouse College. I decided to put sports behind me and

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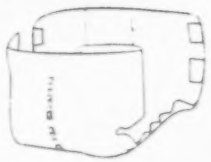

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Circle #14

concentrate on my studies. Initially, I thought I might become a doctor, but I ended up majoring in business.

Just before finishing college, I heard there was going to be a sports competition for amputees in Statesboro, Georgia. I got all excited because although I hadn't stayed involved in organized sports, I was still in pretty good shape.

It was my first amputee meet ever, and my first attempt at any track and field activities. I signed up to run the 100-, 200- and 400-meter races—and I broke world records in all three events. I also tried the high jump and the long jump, and I broke national records in both. This competition was the first time I'd ever met other amputees who were active like me.

World record

Several unexpected highlights of my track and field career occurred at the 1988 Paralympic Games in Seoul, Korea. I was competing in the 100 meters, an event in which I was undefeated. The regular Olympics and the Paralympics were being held at the same venue, and my mom and dad were there at this huge stadium waiting to see me compete. So picture this: the gun goes off and I dash out of the starting blocks. I'm 15 meters into the race—in the lead—and my leg breaks in half! You're talking about a big defeat, because this was a race in which I was virtually assured of a gold medal.

I didn't get a medal in the high jump either. So, it all came down to my last event, the long jump, in which I had never medaled internationally. A Canadian, Arnie Bolt, the world record holder in the high jump, was also favored in the long jump. Sure enough, on his third jump, he broke the current world record. But in *my* third jump, I broke the record he had just set. I came away with the gold medal. In the years since, the long jump has become my main event.

Hop, skip and a jump

After Seoul, prosthetics technology started to catch up with the activities we were doing. I got a new running leg—the weirdest-looking thing I'd ever seen. There was no wood in it; it was all alloy metals and plastics. This was the first leg that could allow me to run leg-over-leg. But I told the prosthetic ist, "Hey, I broke the long jump world record with my hop-skip run. I'm comfortable with it, and I'm going to stick with what works."

At the 1992 games in Barcelona, Spain, the stadium was packed—the Europeans really love track and field. In the midst of my concentration before the long jump, everyone in the stadium started clapping rhythmically. When I started to run, they started clapping faster and faster. It was electrifying, and in my first jump, I broke the world record.

But it was probably the shortest-lived world record ever, because in his first jump, the West German athlete that followed me jumped further. And he used the leg-over-leg running style. I came away with the silver medal, finally convinced that I needed to run leg-over-leg. Today, with an even newer leg, I'm running leg-over-leg and looking to recapture my world record at the 1996 Paralympics, right here in Atlanta.

I think the world will be amazed and impressed with how rapidly Paralympians are closing the gap between themselves and Olympic athletes without disabilities. For example, a double amputee [U.S. athlete Tony Volpentest, a double arm, double leg amputee] now runs 100 meters in 11.6 seconds—only 1.7 seconds off Carl Lewis' world record.

Before a workout, Mead changes from his regular prosthetic leg (left, on bench) to a special, light-weight, high-tech sports prosthetic.

Parents as partners

A parent who wants his or her kid with a disability to get involved in sports must be prepared to be that kid's partner. Mostly, kids need support from their parents. They need their parents to cheer them on, to encourage them to keep pushing and to allow them to share their concerns.

My parents are a good example, particularly because I was a real financial liability to the family. I kept tearing up my leg, and they had to keep paying for repairs. They could have shown some reluctance to do that; but they didn't. They just kept encouraging me to be as active as I wanted to be. They were my partners in the very best sense of the word. **EP**

About the Paralympics...

The Paralympic Games began as the International Wheelchair Games, first held in 1948 in London. In 1960, the competition was renamed the Paralympics. Over the years, the games came to include athletes with a variety of disabilities including visual impairments, paraplegia and quadriplegia, cerebral palsy, amputation and dwarfism.

In the next Paralympics, athletes will compete in 17 different sports including track and field, swimming and volleyball. The 10-day games will be held in Atlanta in 1996, following the summer Olympics. The Atlanta Paralympic organizing committee has planned a number of youth and education programs to coincide with the event. These programs include a "Paralympic Day" in local schools, a Paralympic youth sports camp and a mentor program. For more information about the Paralympics or any of these programs, contact the 1996 Atlanta Paralympic Games, One Atlantic Center, 1201 W. Peachtree St., Ste. 2500, Atlanta, GA 30309-3448; (404) 588-1996; (404) 724-2811, fax.

Fighting for Haley's Life

"Ordinary" parents take on an insurance giant

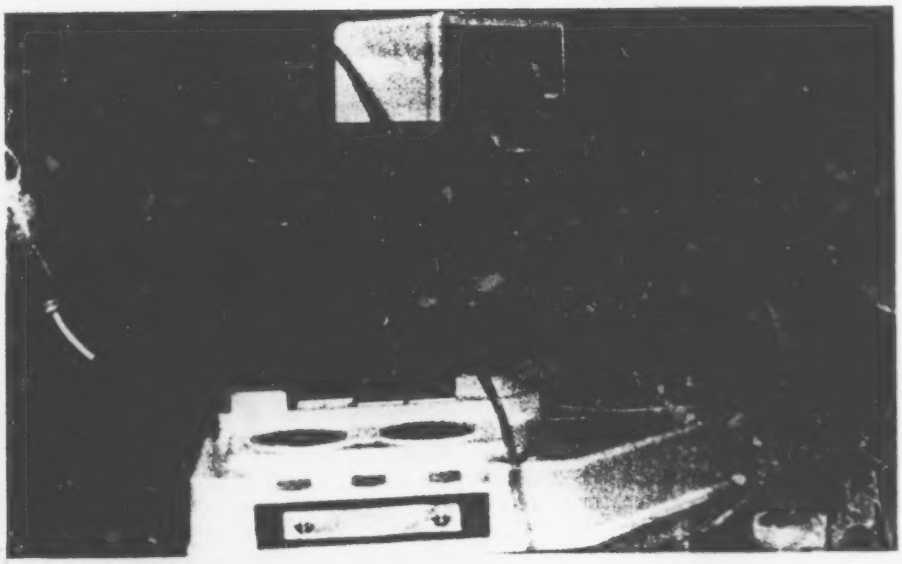
BY JUDY ENGLEMAN

In the November 1995 issue of EXCEPTIONAL PARENT, *Health Insurance Troubleshooter Richard Epstein responded to a question from a family battling their private insurance company for coverage of the special formula their daughter needed to survive. In this article, mother Judy Engleman shares the story of their family's struggle.*

Haley Engleman, 4, plays with her toys as her mother and father look on.

Our family has recently come to the end of a four-year battle with Blue Cross, Blue Shield of Western Pennsylvania. In those four years—a time fraught with frustration, fear, despair and loneliness—we fought the hardest personal war we could ever have imagined. No one should have to endure what our family went through to obtain basic, life-sustaining help.

The struggle began on August 1, 1991, when our daughter, Haley, was born with two rare genetic disorders, Opitz syndrome and Turner syndrome. Since birth, Haley has faced a multitude of medical complications and has undergone numerous surgeries. She is fed primarily through a gastrostomy tube in her stomach and has never been fed anything but a predigested formula, the formula that became the basis for our struggle with Blue Cross.



Haley enjoys playing in her toy kitchen.

At what price life?

Haley's formula is extremely expensive. In the beginning, it cost about $400 a month. By the time Haley was four, her new formula cost nearly $20,000 a year. Nightly, my husband Tom and I tried to figure out how we would come up with money for the next day's formula.

Somehow, we always managed. When we did not have cash to purchase the formula, we charged it. When we reached the limits on our credit cards, we re-mortgaged our house. When we needed still more money, we sold our wedding rings.

Tom works full-time and has private insurance—Blue Cross. Yet Blue Cross steadfastly refused to pay for Haley's formula because they never cover "dietary and nutritional supplements."

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PHOTOGRAPHS BY MARC FADER, PITTSBURGH TRIBUNE-REVIEW

We tried to make them understand, backed up with verification from Haley's doctors, that because Haley does not eat or drink anything else, her formula can in no way be construed as "supplemental." Despite our phone calls, letters and appeals, Blue Cross continued to deny us. It seemed painfully obvious that they did not care about the life of our daughter.

Eventually, Tom and I were forced to apply for Social Security Income, Medicaid and WIC (Women, Infants, and Children—a program that provides vouchers for the purchase of certain foods, including some special formulas). We didn't want to do it. We thought our private insurance should cover Haley's formula; we didn't feel right about accepting help from government programs that exist for people who have nowhere else to turn. Each time we applied for another program, we signed away a little more of our pride and dignity. But we had no choice. Eventually, all three government programs came to our aid.

Still, we never stopped asking Blue Cross for help nor ceased in our attempts to make them change their policy. We called for grievance hearings with the company; we made appeals to the Pennsylvania Insurance Commission and the Pennsylvania Department of Health; we sought and received support from our district's representative in the state legislature, Greg Fajt. None of our efforts made any difference. Blue Cross continued to deny us coverage because, as they told us at one point, they "have always done it that way."

Going public

Our family was faced with one last option: we went to the media. With the help of many caring television reporters and a compassionate editor, reporter and photographer at the *Pittsburgh Tribune-Review*, we brought our story out into the open.

Going public was not a satisfying strategy—we lost so much privacy—but ultimately, it led to a victory. Blue Cross began to respond. Although the company finally agreed to pay for Haley's formula, we knew it wasn't the

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Amber Engleman, 9, watches as her parents, Judy and Tom, change the dressing on Haley's gastrostomy.

Legislation Could Make the Difference

Although Haley Engleman's medical condition may be unique, her need for a predigested formula is not. Many children have conditions that severely impair their ability to take in and digest a regular diet.

More than 50 different formulas are designed for enteral administration (delivery to the intestines by mouth or tube). These formulas vary in composition—the source and proportions of fat, protein and carbohydrate, as well as the amounts of vitamins, minerals and electrolytes—to meet highly specific nutritional and metabolic needs. Some are nutritionally complete and can be used as a child's sole source of nutrition; others are supplements, intended for use in a diet that also includes other foods. Some formulas are palatable enough to be taken orally; others must be delivered by tube.

These formulas have two common denominators—their cost, which is substantial, and their exclusion from insurance coverage by many companies. For families with children who require one of these formulas, the financial consequences can be devastating.

Guided by laws already enacted in some other states, I am working with Pennsylvania state legislators to introduce a bill that would require insurance companies to cover these formulas when they are medically necessary. Legislation to assure coverage for formula needed by patients with phenylketonuria (PKU) has already been proposed. Although well-founded, the limited scope of such a law, if enacted, would leave an enormous number of equally-deserving patients without formula coverage. With the support of families and medical professionals, I hope to convince legislators of the need to include coverage for all children with disorders requiring the use of specialized enteral formulas. I have contacted members of the House Insurance Committee to help them understand both the medical complexity of the problem and the scope of the law that will be necessary to save my patients. A thoughtfully-crafted law should compel insurance companies to support the medically-defined nutritional needs of our children. I expect insurance company lobbyists to oppose this type of legislation, but I believe the health of any company's profit margin should be inconsequential compared to the health of a child like Haley.

—Philip E. Putnam

Dr. Philip Putnam is Haley Engleman's pediatric gastroenterologist at the Children's Hospital of Pittsburgh.

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importance of Haley Engleman's life that convinced them to act: it was the risk of exposure.

Ordinary family, extraordinary circumstances

For us, our daughter has always been the most important part of this struggle. Haley is the one who gave us the strength to fight so hard, for so long. When we remember that she has not been freed from her problems and pain, our victory can seem hollow. But she is still alive.

And now that they are finally paying for the formula, we have seen a different side of our insurance company. Blue Cross CEO William Lowry has vowed to help us pay for the formula as long as Haley needs it; the company has even reimbursed us for the formula we purchased over the last four years. Seeing a more caring side of Blue Cross has brought us not only financial relief, but also peace of mind.

On the other hand, Blue Cross has not changed its policy. They have set up a special fund for Haley; they are paying for her formula, but, technically, they are not "covering" it. I will continue my quest to make Blue Cross see that they must change the way they "have always done it" so every family does not need to go public to win this type of battle. That fight takes a huge toll. Our family has lost so much more than Blue Cross can ever reimburse.

We are an ordinary family who happened to find ourselves in an extraordinary situation. We are not rich. We do not have clout. Yet we were able to accomplish this monumental feat. I hope our story will help others see that they too can enact change, or at the very least obtain aid for themselves and their family. **EP**

Judy Engleman lives in Pittsburgh, Pennsylvania with her husband, Tom, and her two daughters, Haley, 4, and Amber, 9.

Statement from Blue Cross of Western Pennsylvania:

On October 10, 1995, President and Chief Executive Officer William M. Lowry announced that Blue Cross of Western Pennsylvania has set aside funds to aid Haley Engleman, a local child with a rare combination of illnesses.

Haley's medical conditions require her to take a nutritional supplement to sustain her life. The group health program under which Haley is covered does not provide nutritional supplements as a covered benefit. Blue Cross is not aware of any other health insurance carrier that covers nutritional supplements.

"These funds demonstrate our continuing commitment to our social and community mission," Lowry said.

The decision to provide the funds was made on an individual case basis due to the unique needs of this child. Blue Cross of Western Pennsylvania will assist in covering the costs of the special formulas that are life-sustaining and the sole source of Haley's nutrition.

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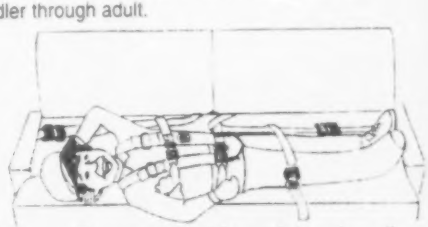

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READERS TALK ABOUT: Early Intervention

Federal law—the Individuals with Disabilities Education Act (IDEA)—requires all states and territories to provide early intervention and preschool special education services to young children with disabilities and special health care needs. State-by-state contacts for these services are listed in EXCEPTIONAL PARENT*'s 1996 Resource Guide (January 1996: "Early Intervention Directory," pp 101–104).*

A Special "Thank You"

Nothing in my 17 years of teaching special education students ever prepared me for the enormous task of parenting a child with disabilities. But ready or not, in April 1993, our son, Clifford, was born eight weeks premature with multiple disabilities and a wide range of health disorders. After two months in the NICU and no diagnosis, Clifford's doctors, believing he would not live long, told us to just bring him home and let nature take its course. At that point, early intervention was the last thing on my mind; I could focus only on the goal of day-to-day survival.

Clifford Conger (front center) enjoys the company of his classmates, Natalie (left) and Marissa (right). With the children is special education teacher Mary Rouse.

In retrospect, however, our family's survival was greatly influenced by our county's early intervention program. My first encounter with early intervention staff came when I halfheartedly brought four-month-old Cliffy to the High Risk Birth Clinic in Binghamton, New York. I was afraid to hear how low-functioning my son was, but the teacher in me wanted to know his developmental levels and whether his vision and hearing were normal. At home, we had seen no reaction to sound and he would only move his head to one side. A close friend—a teacher of students with visual impairments—had given me some ideas for stimulating his vision. So it was that I bravely walked into the clinic that day clutching my older daughter's Cinderella light-up wand to show the professionals what Clifford and I had been doing at home.

I never expected to find such positive and caring people. When I broke down in tears over my frustration at producing a child with disabilities and at my inability to understand his needs, the team members offered the support I so desperately needed, praising my efforts to work with Cliffy. They introduced me to the clinic's parent support group and called me almost every day—just to see how things were going. The clinic nurse made a home visit, taught me infant massage to help with Clifford's constipation and offered advice on nutrition.

Through the early intervention program, Clifford began receiving in-home speech, physical and occupational therapies. And after every therapy session, the home health aide worked with Clifford to reinforce the new skills he was learning.

Nothing came easily. I never dreamed a child would need to *learn* how to hold a bottle! Since both my husband and I worked, we had little time to practice these skills with Cliffy. Our evenings were devoted to cuddle time with both children, and to writing lots of notes for therapists and home health aides.

But slowly, everyone's hard work began to pay off. Clifford, the child with such a bleak prognosis, finally started to respond to his surroundings and to acquire new skills. The only thing still missing was interaction with children his own age. By the time he was 16 months old, Cliffy had started to resist his at-home therapies and wanted only to be held and cuddled by his home health aide. In my heart, I knew it was time to "push him out the door" and integrate him into the real world.

Because Clifford was still considered medically fragile, some health care professionals opposed a switch from in-home therapies to a center-based program. And I'll be the first to admit that Cliffy's first few months at the Handicapped Children's Association were not easy. But as time went on, he gradually began to interact with the other children. I was so proud when his teacher sent me a note saying that Cliffy had crawled over to the sand table, pulled himself up to a little girl's chair and tried to push her off. Clifford was finally telling everyone that he wanted to join an activity!

In two years of early intervention, we have made many changes in the services our family receives and have held endless meetings to update goals in Clifford's program. Through this process, I have become further involved in the early intervention system—attending county-wide meetings, serving on the respite committee, acting as a parent representative and, very recently, becoming a co-chair of the local early intervention council.

I want to encourage other parents to fight for what they feel is right for their children without worrying about "making waves" along the way. Parents know their children best, and if they don't advocate for the necessary services, who will? I *know* Cliffy would never have made such progress without the program at the Handicapped Children's Association and all the in-home therapies he received prior to starting school. I share his story in part as a special "thank you" to all the wonderful people in Clifford's past and present, who have never given up on him.

—Brenda Conger
Vestal, New York

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT*, when readers will be talking about:*

- **Parenting twins when one or both have disabilities** (May issue; deadline March 1)
- **Twenty-five years of EXCEPTIONAL PARENT:** For our anniversary issue, tell us what the magazine has meant to you (June issue; deadline April 1)
- **Work and family:** How do you strike a balance? How have your employers been helpful.... or not helpful? (July issue; deadline May 1)
- **Positive health care stories:** We've all heard the horror stories; now tell us about the health care professionals who have made a *positive* difference for your child and family. (August issue; deadline June 1)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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Angels from Early Intervention

Seven years ago, we had a healthy baby boy and parenthood was easy. Six months ago, we had another baby. This time, we knew things were going to be different.

Our daughter, Brianna, was born prematurely, resulting in many medical problems. One of her scariest conditions was apnea, which caused her to stop breathing frequently. She also had gastrointestinal reflux (severe heartburn).

Needless to say, we were more than a little nervous about bringing Brianna home from the hospital. I gave up my job to take care of her, but after a few weeks of trying to understand and cope with her many problems, I felt like I was at the end of my rope. When a friend called to see how the baby was doing, I burst into tears. I told her how scared and alone I felt. My friend, who has a son with special needs, asked me if I'd called early intervention.

Early intervention? I'd never even heard of it! After asking my friend to explain the program, I contacted early intervention that same day. The next week, a family coordinator visited our home. When she told me about all the available services that could provide help for Brianna and support for the rest of the family, I didn't know where to start. The program also offered respite care so I could spend some much-needed time with my older child, Zach. I felt as if a heavy burden had been lifted off my shoulders.

As the months go by and my daughter's needs increase, I've found I can always count on early intervention. Our family coordinator helps me in so many ways—she's both an information resource and a friend.

Efrain Sanchez and daughter Brianna manage to find a shady spot at the beach.

Currently, Brianna receives in-home therapies and also participates in a small group program outside the home. When we see Brianna smile after doing something for the first time, early intervention seems truly heaven sent. Her doctors say she is really making great progress, and we know we have early intervention to thank.

—Lisa Sanchez
Savannah, Georgia

Listen to Parents!

When our daughter, Katie, who has pervasive developmental disorder (PDD), was two years old, she began an early intervention program through our local child development center. We lived in a rural area and found the limited help and knowledge about our child's disability very frustrating.

I read as much as I could and tried to share some of the things I was learning with the professionals who worked with my child. I knew my daughter needed one-on-one speech and occupational therapies for at least several hours a week. But the program would provide only one hour of "play therapy" at home and another one or two hours at the center. Eventually, we were forced to move to a bigger city where appropriate help was available.

Katie Hallstrom, now 5, enjoys a Halloween party at the developmental preschool program she attends in Boise, Idaho.

Our daughter's situation is much better now, but I will never forget my frustration and the pain of being ignored by "the professionals." The people who work with our children should admit that we are the ones who know our children best. The early intervention program we dealt with did not look at the needs of individual children, but seemed to care only about their budget. Every day I thank God that we were able to move, but I constantly worry about families who cannot escape similar situations.

—Kandy Hallstrom
Boise, Idaho

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A Child First

Our family's initial experiences with early intervention taught us more about advocacy than therapy. When we first entered the early intervention program, my son was assigned to a therapist who was the most insensitive person I have ever met. At that young age, Ian, who was born prematurely and has cerebral palsy and a visual impairment, became easily overstimulated by environmental events. He also seemed to need direct contact to interact with other people. If someone touched him while talking softly, he usually responded very well. When I explained this to the therapist, she informed me that this type of approach would interfere with her therapeutic methods. After a few sessions, Ian became totally unresponsive to her: he would try to engage his nurse or me in an interaction while completely ignoring the therapist's attempts to work with him.

"We love this photo of Ian," writes his mother, "because it shows what a happy child he is."

At that point, the therapist told us we would have to leave the room because our presence interfered with Ian's therapy. This new development upset me greatly. How could I learn to work with my son if I couldn't be present at his therapy sessions? The last straw came when this therapist blithely told me I had my "head in the clouds" if I couldn't see that Ian would not attain any of the skills I hoped for.

Thankfully, this story has a happy ending. Our family was put on a waiting list for another provider, and the people who now work with Ian have the most positive attitude possible. It is so wonderful to work with people who can see my son's potential. His therapists touch him, talk to him and make every therapy session a happy and fun experience. And why shouldn't he have fun? After all, he is a child before anything else.

—Jennifer Bonner
Pennsville, New Jersey

A Winning Team

My daughter, Nicolette, was born seven weeks premature; she was also born with spina bifida. Nicolette had surgery the day after her birth and came home from the hospital when she was three weeks old. Soon thereafter, we first heard about early intervention. Through this program, Nicolette began receiving physical and occupational therapies and other special education services at two months of age.

At her first birthday party, Nicolette Varvaro enjoys a cuddle with her dad.

Nicolette, now 16 months, enjoys doing age-appropriate activities with her occupational therapist, Jude, and her special education teacher, Dawn. We are especially proud of the progress she has made with Judy, her physical therapist. Judy has worked with Nicolette from the start, guiding her through rolling, rocking, crawling and now cruising in a walker. We know Judy's work is much more than a job; each of Nicolette's accomplishments has meant as much to Judy as it has to our family. We feel very lucky to have such a caring person in our lives.

The staff at our early intervention center, Programs for Special Children in Staten Island, New York, has been there for every member of our family. I usually stay in the room while Nicolette's therapy sessions take place. Her therapists teach us what we need to know to work with Nicolette at home.

The therapists at our center understand the importance of family. They understand that this is *our* child and that it can be very difficult for any family to have people coming into their home and handling their child. It can be hard to have a baby up from her nap, fed and ready for therapy, and I know Nicolette's therapists understand if I sometimes have to cancel a session.

It can be hard on siblings, too. Our four-year-old son, John, used to get upset that he couldn't "play" along with Nicolette's therapy "games." But her understanding therapists made things easier for him by trying to give him some special attention, too.

All in all, the benefits of early intervention far outweigh any inconvenience. Our goal is to help Nicolette be the best she can be, and I know we are accomplishing that. It's the combination of family and professionals that makes for a winning team!

—Patricia Varvaro
Staten Island, New York

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Looking Forward to a Brighter Future

Abbi Durham, 3, and brother Tampall, 17, anxiously await Santa's arrival.

Our daughter, Abbigail, suffered anoxia (lack of oxygen) at birth, leaving her with a diagnosis of cerebral palsy. She has profound developmental delays complicated by sensory defensiveness. The prospect of raising a child with special needs was nearly overwhelming, and we knew our lives were headed for some major changes.

A few days after Abbi was released from the hospital, a team from Sooner Start, Oklahoma's early intervention program, came to our home to assess our daughter. At six weeks, Abbi was terrified of every new sound, sight and smell. It was evident that hands-on therapy would be difficult at best, so the therapists set about teaching *us* to work with our child.

With their guidance, we set goals for Abbi and began to plan for her uncertain future. We learned to accommodate her special needs and make necessary adjustments to provide a nurturing environment. Abbi's progress was slow, but we never lacked for encouragement. Her therapists shared our laughter as well as our tears and became an integral part of our extended family. Their enthusiasm for Abbi's every accomplishment, no matter how small, matched our own.

Abbi just turned three and is now making the transition from early intervention to preschool. She still can't sit unsupported but is the "queen of all she beholds" as she sits in her push chair, grasping objects on her tray and dropping them to the floor. No longer terrified of physical contact, she goes to her therapists with little urging and enjoys their attentions.

Because of our early involvement with this team of therapists, our precious daughter's social, motor and cognitive skills have improved. Thanks to early intervention, we are looking forward to a much brighter future.

—Patt Durham
Wetherford, Oklahoma

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With a favorite doll in tow, two-year-old Shannan enjoyed an outing to a park near her Englewood, Colorado home.

"Lucy"

by Julie Allen

You loved her the instant you saw her, with her flaming red hair and her deep green eyes. She had a smile that glistened mischief, even though it was painted on her face. Daddy and I struggled to come up with a name for her. She was your seventh doll; we were running out of names that you liked and we could remember. When we offered "Lucy" as a choice, your eyes lit up with agreement! "Good," we thought to ourselves, "This one will be easy to remember."

That was just a year and a half ago, Shannan. It was a difficult time for all of us. You were 20 months old and you couldn't talk. But you tried very hard to communicate. You could scream. And you could smile and nod. But we often wondered how much more was trapped inside your head.

We spoke to you as if you understood everything we said. With a knowing expression, you encouraged us to continue. We told you all kinds of things—plans for Christmas, stories about family friends, the new recipe we would try for dinner. We talked and talked, all the time hoping that someday you would find a way to talk to us, too.

Shannan, 3, now talks so well that visits to her speech therapist have dropped from once a week to once a month.

Your therapist suggested making a book of pictures to stimulate your attempts at communication. We included photographs of your toys, dolls, cups, clothing and favorite snacks. We included pictures of your toothbrush, bed and family. When you became frustrated, we would rush for the book so you could indicate the picture of the object you wanted. But this method often fell short, especially when you wanted something less concrete than a toy or a snack—something like understanding or sympathy.

Finally, with the help of your speech therapist, you began learning to make the muscles in your mouth work more consistently. We learned to use positive reinforcement to encourage any sounds you made. We worked very hard, and so did you.

Each day you tried to make that mouth work for you. Soon you could make many new and different sounds. You began saying a few recognizable words. We loved hearing you speak and rejoiced in your success.

After months of practice, you could say 20 words. Much of our family's frustration began melting away. We could finally understand our little girl, and we were beginning to catch glimpses of the child yet to come.

Now you are three years old. You are talking so well that we no longer need to go to "speech" each week. Now, we only go for a monthly check-up. Every day, we watch you develop—both mentally and physically. We feel more like a family these days. We are all able to verbalize our needs, wants, successes, disappointments and, most importantly, our love for each other.

This afternoon, while digging through the bottom of the toy box, you found a dolly you hadn't seen in a long, long time—a doll you hadn't played with since a pre-verbal time. As delight danced in your eyes, you plucked her from the pile of forgotten toys and pulled her to your heart. With a screech of joy, you shouted, "Daddy, what's this dolly's name?"

Your daddy didn't remember and with a tender voice, recalling how you had loved the doll and how very important she had been in your life, he said, "I'm sorry, honey. I just don't remember."

Regarding him seriously, your eyes acknowledged his answer. You sat silently for a moment, then grinned broadly and shouted, "I know her. It's Lucy!" **EP**

In a well-stocked playroom, three-year-old buddies Shannan (right) and Madison (left) have all the ingredients for a fun-filled afternoon.

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"Help Wanted: Experience in Education

by Lauren Agoratus

On May 10, 1992, after a difficult pregnancy, I gave birth by emergency cesarean section to a baby girl. Stephanie Maria's arrival was something of a miracle since I had once been told I might be unable to have children.

Shortly after birth, Stephanie went into respiratory distress. The next day, she was rushed to Children's Hospital of Philadelphia, where she was diagnosed with several serious kidney disorders—renal agenesis, renal dysplasia and grade IV bilateral vesicoureteral reflux. My daughter spent her first two weeks of life hooked up to a respirator, heart monitor, intravenous lines and feeding tube. For the next 10 months, per doctor's orders, we lived at home in isolation. We couldn't leave or have visitors for fear of exposing Stephanie to germs and sickness.

Two-month-old Stephanie, cuddling with her father, Steven, was born with several serious kidney disorders.

The game had changed

I had researched daycare options and chosen a provider while pregnant, but Stephanie's fragile medical condition had changed not only the rules, but also the game. Since daycare centers, with their large numbers of children, were no longer an option, we decided to investigate in-home family daycare. Childcare Connections, a local child care referral agency, gave me a list of providers. After interviewing and visiting each one, I chose Lee, a woman who'd had some personal experience with disabilities and medical conditions: her son had attention deficit hyperactivity disorder (ADHD), and her daughter had spent her first few weeks in intensive care.

Before returning to work, I spent two months helping Lee and Stephanie get comfortable with each other. I brought some of Stephanie's things from home so she would be surrounded by familiar objects, and I gradually left her with Lee for longer periods of time. I briefed Lee on the special precautions we take to prevent infection—using white diapers, wipes and tissues without fragrances or dyes, and washing our hands both before and after changing diapers. Lee also had to learn about Stephanie's medications and special diet, which includes a caloric supplement and food thickener. To make things easier, we prepared Stephanie's meals and medications ahead of time.

Unfortunately, although Stephanie was one of only three children in Lee's daycare home, she still came down with frequent illnesses. By the age of 12 months, when her weight had dropped to a mere 10 pounds, we had to take her out of daycare.

"Help wanted..."

With the help of Childcare Connections, we began to search for in-home, one-on-one daycare. I hoped to find a new provider who didn't yet have any other clients. I was willing to pay almost double if a caregiver would agree to take Stephanie only, but I didn't feel a good "fit" with any of the providers I interviewed.

Reading a pop-up book with Mom is the perfect way to spend a lazy summer afternoon.

The agency then referred me to Work/Family Directions, a referral agency specializing in in-home care, where I worked extensively with an in-home specialist. She gave me a manual that included specific information on in-home options—everything from hiring an individual provider or nanny, to going through a health care agency. The manual also provided tips for finding a provider through newspaper ads, senior employment programs or colleges.

We started by placing a few newspaper ads. I initially scared people off by advertising for a person with a "medical or special education background." When I reworded the ad to read "education or health care experience," we got more responses. I prescreened applicants over the phone, being candid about Stephanie's medical condition so nobody wasted any time.

Helpful resources

After an exhaustive search, we found our first in-home provider by combining the resources of the Childcare Connection, Work/Family Directions and our local newspapers. When that provider returned to college, we were able to find another through the same process. We hope she is the last one we have to search for; so far, she has been with us for more than a year. In the course of our searches, however, we discovered a number of other resources that may help other parents of children with disabilities or special medical needs:

• *Health care agencies:* We discovered that many health care agencies provide daycare. These are the most expensive option; however, health insurance may partially cover the cost of this type of daycare if your child has special medical needs. Be sure to get a written predetermination of coverage before beginning this type of service. In our case, because Stephanie didn't require any special medical equipment, our particular

Nanny Lauren Amster would never miss Stephanie's third birthday party!

or Health Care..."

insurance policy would not cover any part of daycare expenses.

• *Government agencies and offices:* Many state and local agencies were helpful to us. For example, the New Jersey Department of Labor prescreened day care providers and set up interviews for us. Other agencies dealing with specific disabilities or early intervention programs may offer emergency, respite or temporary care. We found that a number of these programs also offered on-site group daycare; sometimes specifically for medically-fragile children. Unfortunately, because of our need to keep Stephanie isolated, none of these programs met our needs.

Other potentially helpful agencies include your state's departments of education, human services, daycare licensing, developmental disabilities, special child health services and/or maternal and child health. Also contact your state's childcare advisory council, as well as social services and health departments on both state and local (or county) levels.

• *Informal networking:* In the course of our search, we contacted pediatricians; medical specialists; physical, speech, and occupational therapists; social workers; early intervention workers; school nurses and child study teams. I also talked with other parents I met at church, LaLeche meetings and support group meetings. Of course, we also made sure that family members, friends and colleagues knew of our search.

• *Senior citizens:* We checked with retirement communities, senior citizen centers, senior employment programs and the New Jersey Office on Aging. We found that senior clubs and organizations were willing to let others know of our search.

• *Postering:* We posted ads in churches, stores, libraries, doctor's offices, hospitals, nursing schools, college placement offices and departments of health and education, home health aide classes and at the YWCA. We also contacted local philanthropic organizations such as the Elks, VFW, Kiwanis, and Jaycees, who put up our posters and mentioned our search at meetings.

Peace of mind

Keep careful records and notes on your daycare search. Each time we looked for a child care provider, I kept track of contacts we made, leads we followed and the results of each. My notes made each subsequent search faster and easier.

Yes, Stephanie's special health care needs changed the daycare game for our family. But with a little legwork, we were able to turn up many helpful resources. And when our search was over, we ended up with what every parent looking for daycare wants—the best possible care for our child and peace of mind for ourselves. **EP**

Lauren Agoratus lives with her husband, Steven, and daughter, Stephanie, in Allentown, New Jersey. She works as a customer service representative for Shaklee Corporation. Steven works in national and international medical equipment sales for the Urology Division of Convatech, a division of Bristol-Meyer-Squibb.

Although Stephanie still receives all her therapy at home, she now enjoys frequent outings to a church playgroup, library storytimes, the Discovery Zone and Gymboree. Lauren and Steven hope she will be able to begin attending preschool this year or in 1997.

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Circle #24

Child Care and the ADA: Litigation Updates

by Maria Gil de Lamadrid

The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of a disability for many private businesses—including daycare centers (with the exception of church-operated programs). This means that child care programs, including family daycare homes, must make "reasonable accommodations" to give children with disabilities equal access to program participation. "Reasonable accommodations" may include revision of policies and procedures, removal of physical barriers, provision of adaptive equipment, curriculum adaptations, changes in staffing patterns and additional staff training.

The ADA does provide a few exceptions under which child care programs may exclude children with disabilities. Under one very narrow exception, for example, a provider is allowed to exclude a child whose condition poses a "direct threat" to others. Any decision to exclude a child on this basis must be made using objective information—such as medical or psychological evaluations—and cannot be based on sheer speculation. In addition, if the threat of harm can be eliminated through "reasonable accommodations" in the program, these accommodations must be made.

The ADA also permits a child care provider to exclude a child with a disability if accommodating the child requires: 1) changes in policies, practices or procedures that "fundamentally alter the nature of the program;" 2) provision of equipment or services that "fundamentally alter the nature of the program" or that represent an "undue burden" (significant difficulty or expense) on the provider; or 3) architectural changes that are not "readily achievable" (easily accomplished without significant difficulty or expense).

The definition of "undue burden" and "readily achievable" depends largely on a program's resources—things like budget, space and child-staff ratio. For example, a large chain of child care programs that typically provides transportation services may be able to buy a wheelchair lift for a van; for a small family daycare home, however, such a purchase would create an "undue burden."

A recent settlement between KinderCare and the family of 10-year-old Jeremy Orr, shown here during a 1995 visit to DisneyWorld, ordered KinderCare to allow Jeremy to attend an after-school with a personal assistant and to place him in an age-appropriate class. Previously, the child care center had kept Jeremy in a classroom with two-year-olds, despite his age and size.

Looking at relevant cases

Since the implementation of the ADA, many questions have arisen about the meaning and precise application of the law as it applies to child care programs. While many of these issues are worked out informally between parents and child care centers, some have proceeded to a more formal means of dispute resolution—complaints filed with the Department of Justice or actual lawsuits. The resolutions of these complaints or lawsuits help to clarify the ADA's meaning and application, and provide guidelines that can help people avoid similar disputes. What follows is a brief summary of some of the issues and most relevant recent developments.

Licensing barriers

The ADA clearly requires child care programs of all sizes to care for and accommodate the needs of children with disabilities whenever they are reasonably able to do so. Additionally, the ADA does not permit state agencies, such as those responsible for licensing child care facilities, to create or enforce regulations that might prevent the participation of children with disabilities in child care programs. Unfortunately, however, pre-ADA licensing regulations in some states have had that effect.

In Connecticut, the parents of a child with diabetes sued a child care program when that program refused to perform the finger prick blood glucose test on the child. The program based its refusal in part on the understanding that state licensing regulations would not permit this procedure to be performed in child care. The suit was quickly settled with an agreement that the child would be enrolled and would have the blood glucose test done at a nearby pediatrician's office.

The parents, recognizing that the child care center had few options in light of existing licensing regulations, then sued the state of Connecticut, alleging that the state regulations interfered with their child's rights under the ADA and Connecticut's own anti-discrimination law (*Breen v. State of Connecticut, Department of Public Health and Addiction Services*). That suit was recently dismissed when a judge ruled that the parents had ignored the requirement that they have the case reviewed by the appropriate administrative agency before filing the suit in court. When the court dismissed the case, the parents asked the Connecticut Board of Examiners for Nursing to issue an administrative judgment stating that Connecticut law allows non-nursing child care staff to perform blood glucose tests. If their petition is denied,

the parents will probably have the right to return to court.

Any ruling in the *Breen* case may influence the outcome of disputes occurring as the result of similar regulations in other states. For example, California licensing regulations include a restriction, similar to Connecticut's, against performing "medical procedures" in licensed child care centers.

Another case involving regulatory barriers arose in Kansas, where licensing regulations governing the number of children that can be cared for in a given center are based not only on the age of the children, but also on their ability to walk. For example, a center may be licensed to care for a certain number of children aged 12 months to two and a half years who can "walk alone." In *Ireland v. Kansas District of the Wesleyan Church*, parents of a three-year-old child with multiple disabilities, including mental retardation, cerebral palsy and a seizure disorder, filed suit against a child care program that attempted to dismiss the child because he had become too old for the infant room, but did not—and could not—qualify for the toddler room due to the walking requirement. The suit was filed under Section 504 of the Rehabilitation Act, rather than the ADA, because the child care program was church-operated and thereby exempt from the ADA. However, because the child care program received federal subsidies, it was covered under Section 504, which has virtually identical requirements to reasonably accommodate children with disabilities. So far, the federal court has granted a temporary order prohibiting the child care program from dismissing the child while the case is still under consideration.

Regulatory barriers such as those involved in the Connecticut and Kansas cases can pose a very real problem for parents who are desperately trying to find quality care for their children with disabilities. But these regulations may also present a dilemma for the child care providers caught in the middle—between their legal duty under federal law to provide accommodations to children with special needs and the state licensing regulations that prevent them from providing these accommodations.

In such situations, it is best if parents and child care providers can work together to resolve the problem. Presenting a united front, parents and providers can bring the situation to the attention of the appropriate state agency, giving the agency a chance to resolve the problem before a lawsuit is initiated. The state agency may be able to grant a waiver from the regulations, making an exception for a particular case. Or the agency may be able to change its licensing regulations to comply with the ADA.

If the situation between parents and child care providers becomes adversarial, parents do have the right to sue a provider or the state, or both. However, it is important to remember that the licensing regulations may leave a child care provider with limited power to remedy the situation, and that a lawsuit against the state may be ultimately necessary to force a change in the regulations. Parents who are considering such a lawsuit may want to consult an attorney.

Denying Care or Accommodations to Children with Disabilities

Most accommodations needed by children with disabilities in child care are not prohibited through state regulation. This means it is entirely up to child care programs to decide whether requested accommodations are "reasonable" or not. The ADA does not allow programs to automatically deny care to children with disabilities; each child's needs must be assessed on an individual basis. But given the vagueness of the ADA guidelines for determining reasonableness, relevant cases can provide guidance.

HIV status

In California, the case of *Morril v. Mexican-American Opportunity Foundation* was a lawsuit filed on behalf of a three-year-old boy whose mother had died of AIDS. The child care center allegedly refused to continue caring for the boy until he was tested and found to be "free of AIDS." However, the ADA is very clear that children cannot be refused care based solely on their HIV status, or the HIV status of someone closely associated with them. Child care programs are also clearly prohibited from requiring testing and/or disclosure of the HIV status of children under their care or applying for admission, or of anyone closely associated with the children. This case was settled in favor of the child.

Segregation from peer group

A case in Minnesota, *Rodenberg-Roberts v. Children's World Learning Centers*, addresses the extent to which a center may segregate a child with disabilities from his or her own age group. In that case, the parents of Brandon Roberts, a three-year-old child with disabilities, sued a child care center that segregated Brandon from other children his age due to his special needs, which included low weight, the need for assistance in feeding himself, self-injurious behavior, attention deficit hyperactivity disorder (ADHD) and seizures. The father was an employee of the center, and the center allegedly required that Brandon be cared for only in the room where his father worked, rather than in an age-appropriate room. The ADA has strong language requiring inclusion of children with disabilities. This case is scheduled for trial early this year.

Need for personal attendant

Two separate lawsuits filed against KinderCare Learning Centers, the nation's largest child care chain, have recently reached initial resolution—one through court decision and one through court-approved settlement. Both dealt with similar issues involving care for a child who needed a personal attendant while in care.

The case of *Roberts v. KinderCare Learning Centers* arose when the parents of four-year-old Brandon Roberts (see *Rodenberg-Roberts v. Children's World Learning Centers* above), dissatisfied with the care he was receiving at Children's World Learning Centers, attempted to enroll Brandon in full-time care at a KinderCare Learning Center. Brandon had been provided with a state-funded personal care attendant who would accompany him to child care; however, in the past, these attendants had been unreliable. In addition, the aide would not be available full-time. KinderCare concluded that Brandon's care would require the center to regularly provide a staff person to serve as Brandon's aide, and they refused to care for Brandon at times when the program would have to supply Brandon's attendant.

Brandon's parents sued KinderCare, alleging that the center's acceptance of Brandon only when accompanied by his

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aide represented a failure to reasonably accommodate him as required by both the ADA and Minnesota state law. In response, KinderCare argued that it had no responsibility to provide one-on-one care because doing so would "fundamentally alter the nature of its group care program." KinderCare also stated that the salary for an additional staff person to care for Brandon would be twice the amount of Brandon's tuition—thus creating an "undue financial burden"—and that the alternative solution of administrative staff members serving as Brandon's aides would prevent them from carrying out their usual job responsibilities.

Based on Brandon's IEP and the testimony of his mother, a district court in Minnesota concluded that Brandon did require a one-on-one aide in the child care setting. The court agreed with KinderCare's position that the center was in the business of providing "group care," the nature of which would be "fundamentally altered" by their provision of a one-on-one aide for Brandon. The court also agreed that requiring KinderCare to provide such an aide would create an "undue financial or administrative burden" on the program. Brandon's attorneys have appealed the case to the Eighth Circuit Court of Appeals, but until the circuit court issues a decision on the case, the district court decision remains in effect.

A recent settlement between the Department of Justice and Sunshine Child Center, a Wisconsin daycare program, requires the program to make "reasonable accommodations" for four-year-old Belinda Brock, who has cerebral palsy. These accommodations include assistance with Belinda's leg braces and diapering, placement in an age-appropriate class and removal of existing architectural barriers.

Shortly after the *Roberts* decision in Minnesota, a court-approved settlement was reached in a California case, *Orr v. KinderCare Learning Centers*, involving the same issue of group versus one-on-one care. In that case, KinderCare refused to allow Jeremy Orr, a 10-year-old boy with developmental disabilities, to attend an age-appropriate class in an after-school program, even when accompanied by a personal aide. Jeremy had been receiving care from the program for a number of years but had gradually come to require more one-on-one attention. Over the years, the program had kept Jeremy in a classroom with two-year-olds, despite his age and size.

To enable Jeremy's participation in the activities of an age-appropriate class, community agencies agreed to provide the services of a personal aide at no cost to the family or program. The program, however, refused to continue caring for Jeremy, taking the position that including a child with a personal assistant would fundamentally alter the nature of the group care offered and was not a "reasonable accommodation."

Represented by the Disability Rights Education and Defense Fund (DREDF), Jeremy's parents filed suit in March 1995, and the U.S. Department of Justice, the enforcement agency for the ADA, entered the case on their behalf. A quick settlement ordered KinderCare to allow Jeremy to attend KinderCare with a personal assistant, to place Jeremy in an age-appropriate class and to educate its staff about the ADA.

In some respects, the settlement in the *Orr* case is consistent with *Roberts* and, when read together, *Orr* may help to pinpoint the way the *Roberts* decision should be applied. While *Roberts* indicates that child care programs may not neccesarily be required to supply, at their own expense, personal attendants for children with disabilities who need one-on-one attention, the *Orr* decision demonstrates that programs may not automatically deny care to children whose families can provide their own attendants.

Significantly, in *Roberts*, the court held that KinderCare would not be required to care for Brandon without his aide, while in *Orr*, both parties agreed that KinderCare will not insist on an aide as a condition of Jeremy's attendance. This difference may be explained by the nature and level of care required for each child. In *Roberts*, evidence showed that Brandon required one-on-one attention to ensure his safety while the court in *Orr* concluded that Jeremy did not require constant one-on-one attention; in fact, he had often been "left to his own devices" while cared for with the two-year-olds.

While the outcomes of both cases are important, it is crucial to remember that they offer only an indication of how similar cases may be analyzed (except in Minnesota, where *Roberts* serves as a precedent at this time, pending the parents' appeal of that decision). The facts of each individual case will determine how the ADA is applied, and even similar cases may have different outcomes if any important facts differ. For example, if a child needs one-on-one assistance only occasionally and/or if existing staff is reasonably able to provide such assistance by shifting schedules and responsibilities, and/or if the existing program tends to provide more one-on-one care than KinderCare, that program might be required to provide such assistance.

A test of the "direct threat" exception

Grist v. State Board for Technical & Comprehensive Education, a South Carolina case, involved a child care center that expelled a child with fragile X syndrome due to behavior (affected by his disability) that had escalated to scratching other children. The major issue in the case had to do with whether or not the threat to the health and safety of other children could have been eliminated through "reasonable accommodations." Before the child was expelled, his parents had agreed to various measures designed to remove the threat, such as having the child wear special gloves to prevent scratching and placing an additional aide (at no cost to

the center) in the child's classroom. In spite of these measures, the child had been dismissed. Under the terms of the settlement, the center agreed to change its policies regarding children with disabilities, to allow the boy to reapply for enrollment and to reevaluate its ability to make reasonable accommodations for him.

Toilet Training Policies

In 1994, a Head Start program settled a case filed on behalf of 10 children with disabilities who were refused admission based on their inability to be toilet trained. This settlement ordered the program to admit all of the children who were otherwise eligible for the program.

In the wake of this settlement, the Department of Health and Human Services, the government agency that oversees the Head Start program, has issued a memo stating in no uncertain terms that Head Start programs "should not deny enrollment to a child on the basis of toileting skills, regardless of whether or not that child has a disability." Emphasizing that a toilet training requirement would screen out children with both diagnosed and as-yet-undiagnosed disabilities, the memo goes on to state that children who are unable to be toilet trained by the time they are eligible for Head Start are precisely the ones most in need of being served by the program.

While toilet training policy guidelines are now quite clear for Head Start, they are not quite so clear for other child care programs. Programs with diapering areas/services within their facility are apparently required to assess whether they are reasonably able to accommodate children unable to be toilet trained due to a disability. However, under limited circumstances, programs without diapering areas/services may be allowed to pass the cost of diapering along to the parents of the child. In the latter case, diapering would be considered "personal assistance" (defined as services of a personal nature, not otherwise offered as part of the general services provided). Such personal services are not required by the ADA. These guidelines are still somewhat confusing and unclear, and under most circumstances, programs should assess whether they can provide diapering services to children with disabilities without passing the case along to the parents.

"Reasonable Accommodations"

A very recent case against a Wisconsin child care program, *Brock v Sunshine Child Center*, is the first ADA case to reach formal settlement between the U.S. Department of Justice (DOJ) and a daycare center. The case arose when the Sunshine Child Center refused requested accommodations to Belinda Brock, a four-year-old girl with cerebral palsy. Belinda required diapering and assistance with removing and putting on her leg braces. Her parents also asked the child care program to eliminate some architectural barriers that restricted Belinda's access to the center's parking area and bathrooms.

The center refused to accommodate these needs, refused to place Belinda in an age-appropriate class because of the need for diapering and, ultimately, refused to continue to care for her. In the settlement, Sunshine Child Center agreed to readmit Belinda, assist with her leg braces and diapering, place her in an age-appropriate class, remove existing architectural barriers in the current facility and ensure that the center's new facility, now under construction, be fully accessible.

Comments from DOJ upon settlement of this case emphasized that necessary accommodations for a child with a disability are often relatively uncomplicated. They also suggested that accommodations such as those required by the Brock settlement would be considered "reasonable." **EP**

Maria Gil de Lamadrid is a staff attorney with the Child Care Law Center (CCLC, 22 Second St., 5th Floor, San Francisco, CA 94105; 415/495-5498). This article has been updated and adapted from an article appearing in the Spring 1995 issue of LEGAL UPDATE, *a CCLC publication.*

For more information...

These resources provide general information about the ADA. They can also answer questions and provide guidance with regard to specific situations or concerns.

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Callers may access recorded information and order publications 24 hours a day. To speak with an ADA specialist from the US Department of Justice, call Monday–Friday, 10 a.m.–6 p.m. EST.

Child Care Law Center
(415) 495-5498 (voice)
To discuss specific concerns, call Tuesdays or Thursdays, 9 a.m.—noon (Pacific Standard Time), or write to Child Care Law Center, 22 Second St., 5th Fl., San Francisco, CA 94105.

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Income Tax Tips

Knowledge of specific exemptions or deductions can be valuable for parents of children with disabilities and/or special health care needs.

Exemptions for dependents

Taxpayers are entitled to a deduction of $2,500 for each "dependent." A person qualifies as a dependent if she or he is related to the taxpayer and if the taxpayer provides more than half of that person's financial support. "Support" is not defined only as necessities, so money spent on gifts and allowances also count toward support. A dependent cannot earn a yearly gross income of more than $2,500. However, if the dependent is under the age of 19 or a full-time student under the age of 24, this income test does not apply. When parents claim a child as a dependent, the child cannot claim a personal exemption when filing his or her own tax return.

Medical Expense Deduction

Taxpayers may deduct unreimbursed medical expenses for themselves and their dependents. Even if your child cannot be claimed as a dependent, if you provide more than half of his or her support, you may still deduct medical expenses. These expenses include health insurance premiums and any medical expenses not reimbursed by health insurance. Parents may take medical expense deductions *only* if medical expenses are itemized on Schedule A, form 1040 (the long form) and if those expenses exceed 7.5 percent of their adjusted gross income.

"Medical expenses" are defined broadly to include amounts paid for "the diagnosis, cure, mitigation, treatment or prevention of disease, or for the purposes of affecting any structure or function of the body." It is easy to recognize the usual expenditures—doctor visits, hospital stays, wheelchairs—as deductible; but a wide array of other costs can also be deductible, as long as the taxpayer can document that a doctor has "prescribed" the item as "medically necessary." Medical deductions that might be overlooked include:

• *Capital expenditures to modify a home:* The deductible amount is the amount of the cost that exceeds the increase in the value of the home, if any, resulting from the modification. Modifications that do not increase the value of the home are fully deductible.

• *Special education and training costs:* A deduction is allowed for the cost of attending a special school if the child's medical condition is such that the school's specialized resources are a principle reason for the child's attendance.

• *Other "medically necessary" expenses related to a child's disability:* These may include transportation costs to and from therapies, specialized toys and computer equipment, television or telephone equipment for individuals with hearing impairments, diapers for an older child who is incontinent, even the cost of a subscription to EXCEPTIONAL PARENT or other specialized publications.

By attaching a doctor's letter explaining your child's disability and listing the items that are "medically necessary," as well as attaching documentation for any unusually high expenses you deduct, the IRS is less likely to question medical deductions or subject you to an audit. Never send originals and always include your name and social security number on anything you attach to your return. Remember that audits can go back as many as seven years—so save all of your receipts and former tax returns related to deductible expenses.

If you have missed deducting a medical expense on a previous tax return, you may file an Amended U.S. Individual Income Tax Return (form 1040X).

Tax Credits

Tax credits are more beneficial than deductions because they are deducted from taxes due, thus decreasing your tax bill directly.

• *Child and Dependent Care Credit:* The credit is for 20–30 percent of your child care expenses, with a limit of $2,400 for one child, or $4,800 for two or more children. To qualify, your dependent must be under the age of 13 or, if older, must be physically or mentally unable to care for himself or herself. You must have paid child and dependent care expenses in order to work, look for work or go to school. To take this credit, file either form 1040 or 1040A.

• *The Earned Income Credit:* To qualify, you must meet one of the following criteria: have two or more qualifying children living with you and an adjusted gross income less than $26,673; have one qualifying child living with you and an adjusted gross income less than $24,396; or, if you do not have a qualifying child, your adjusted gross income must be less than $9,230. A qualifying child does not have to be a dependent; however, the child must meet the requirements of relationship, residency and age outlined in the Earned Income Credit publication. You may claim this credit using any tax form. If the credit exceeds the amount of tax owed, you can get a refund. **EP**

—Ellen Bullock

Where to get free help

The IRS provides free tax services throughout the year. Call (800) 829-1040, voice, or (800) 829-4059, TTY, for scheduled hours. Certain tax materials are available in Braille; for information on Braille materials, contact the National Library Service at (202) 707-5100.

To order free IRS publications, call (800) 829-3676.

The following publications may be especially helpful:

- Publication 17: Your Federal Income Tax
- Publication 501: Exemptions, Standard Deduction and Filing Information
- Publication 502: Medical and Dental Expenses
- Publication 503: Child and Dependent Care Expenses
- Publication 524: Credit for the Elderly or Disabled
- Publication 596: Earned Income Credit
- Publication 929: Tax Rules for Children and Dependents

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Seating and Positioning

Important considerations when purchasing car seats and strollers

by Frederic A. Moritz

Many children with physical disabilities need assistance to best use their abilities and be comfortable while lying down, sitting or standing. "Positioning" refers to the process of providing this assistance in the most effective way. When properly positioned, a child has the postural support to give his or her full attention to participating in the activity at hand—no need to worry about losing balance or falling. A properly positioned child usually has better control of his or her movements (arms, hands, legs, trunk, neck and head) as well. Proper positioning may improve circulation, breathing and digestion; it may also help to prevent some physical deformities, muscle problems and/or skin problems.

For children who have difficulty standing and/or walking, proper positioning for seating is critical to almost all daily activities. To fulfill this need, certain professionals have developed considerable clinical expertise in positioning and seating.

The Complete Seat Pediatric Seating System can accommodate children up to 40 pounds, and fits standard strollers, high chairs and wheelchairs. Photo courtesy of Tumble Forms. See ad on back cover.

Asking the right questions

A team that includes parents and professionals (typically occupational and physical therapists, rehabilitation technology suppliers and, sometimes, rehabilitation engineers and a physician) can work together to determine the specific positioning needs of an individual child. This process requires asking questions about the child's everyday activities. The team should also consider physical characteristics of the child's specific disability. For example, low muscle tone (hypotonia) may require extra support, while rigidity or spasticity may require a different positioning approach.

In some cases, relatively simple systems (for example, using everyday household items like pillows) will be sufficient for a child's positioning needs. Other children will require several interrelated pieces of specialized equipment (sometimes called a positioning "system"). If specialized equipment is required, the team needs to decide whether to purchase commercially available ("off-the-shelf") equipment, create highly individualized ("customized") equipment, or do both.

The key question for the team is this: How much positioning is enough? A more sophisticated system may also be more costly or complicated, more limited in the purposes for which it may be used or heavier for the caregiver to handle. The goal is to provide a successful match between the child's physical needs, the lifestyle of the child and family, and the specific equipment.

Positioning needs of young children

Parents of young children with disabilities may first face the positioning question when considering the purchase of a car seat or stroller. Neither piece of equipment should be an impulse buy. In fact, these purchases require the same kind of research that might go into the acquisition of a new car. Portability and safety are primary considerations for both. And for children with disabilities, the positioning features of a car seat or stroller are equally important.

The Adjustable Back Toddler Chair provides positioning and can tilt up to 20 degrees forward or backward. Photo courtesy of Rifton. See ad on page 3.

The input of all team members is crucial. Therapists can analyze the child's needs and the ways a family's lifestyle may affect equipment use. The equipment supplier can contribute his or her knowledge of available equipment. And parents' observations of a child's needs and behavior can guide both therapist and equipment supplier. In some cases, the child may be referred to a clinic, hospital or technology center to try out different kinds of equipment.

Car seats

Federal Motor Vehicle Safety Standards provide national standards for the manufacture of all car seats. These standards ensure that a car seat, when properly used, will provide adequate protection in the case of a collision. But these standards do not address the positioning and special safety needs of children with disabilities. In fact, for children with disabilities, proper positioning may be an important safety consideration.

The Orthopedic Seat and Car Seat fits many stroller bases, including the Columbia Mobility Base. Photo courtesy of Columbia Medical. See ad inside back cover.

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Putting the Positioning Team Together

Your state's federally-funded Pediatric Technology Program (PTP) can provide a list of clinics, hospitals and other service providers that are knowledgeable in fitting technology to children's needs. To locate your state's PTP, call RESNA's (Rehabilitation and Engineering Society of North America) technology assistance office at (703) 524-6686.

A rehabilitation technology supplier (usually the retail "dealer") is a key person on the team. Therapists, physicians and "satisfied customers" (other parents) can help identify a supplier who is familiar with positioning equipment for young children with disabilities. The National Registry for Rehabilitation and Technology Suppliers (NRRTS), a professional membership organization, can also supply a directory of members; for more information, call NRRTS at (806) 797-7299.

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In addition to evaluation of a child's physical needs, the team considering a car seat purchase needs to think about a variety of practical concerns: How will the car seat will be secured within the vehicle? Will it be moved from one kind of vehicle to another? How much time will the child spend in the car seat? And for how many years will it be needed?

If the car seat is to be used in more than one vehicle, questions of portability and weight become crucial. A heavier, more solid car seat may provide better positioning for the child, but may prove more difficult for the caregiver to handle. It is important to remember that the installation and removal of a car seat often involves crouching, reaching into a vehicle and lifting from awkward positions. The caregiver must be sure to lift safely—bending at the knees to protect the back.

Some car seats can be removed from the car and placed on a "mobility base," which has the functions of a stroller. However, if the child and the seat are to be moved together, their combined weight will increase as the child grows larger. For older, heavier children, parents may need to consider the purchase of a van with a wheelchair ramp or lift and tie-downs for securing the wheelchair in transit.

The Kid-T-Rex is a light-weight, foldable stroller that provides padded, therapeutic positioning. Photo courtesy of Kid-Kart. See ad on page 11.

Strollers

Considerations of weight and portability are also issues to be considered when purchasing a stroller. Some very young children with disabilities can use the same types of low-cost, commercially-available strollers as their peers without disabilities. But as children grow older, their positioning needs often increase, requiring the purchase of more specialized equipment.

The Cruiser Ready stroller has many different positioning accessories. Photo courtesy of Convaid Products. See ad on page 5.

The team considering a stroller purchase needs to find the right mixture of mobility and positioning for a given child. In addition to considering the child's physical needs, the team needs to ask questions about the family's lifestyle and the caregiver's ability to handle various types of equipment: Is the stroller easy to use, fold up and store? Is it sturdy enough to be reliable, but light enough to be carried? How much time will the child spend in the stroller? For how many years will the stroller be needed, and how will a child's growth during that time affect the caregiver's ability to handle the product?

Greater positioning needs may require a more complex and, sometimes, more expensive and/or heavier product. And the more time a child will spend in the stroller, the greater his or her need for proper positioning. As with a car seat, it can be helpful to find a clinic or hospital where parent and child can take a few different strollers out for a "test drive."

Fred A. Moritz is a Boston-based freelance writer.

EXCEPTIONAL PARENT gratefully acknowledges the assistance of the National Registry for Rehabilitation and Technology Suppliers (NRRTS) in the preparation of this article.

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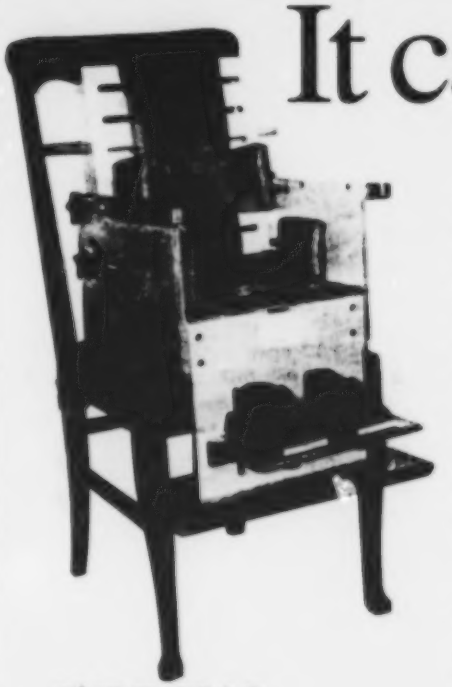

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Circle #131

by Frank L. Brunetti

Trusts for Children With Disabilities

Some parents of children with disabilities can be hopeful that their children will grow up to be financially independent and eligible for adequate and affordable health insurance. Unfortunately, for many children with disabilities, this outcome is unlikely. In fact, many capable adults with disabilities are underemployed and/or ineligible for health insurance due to preexisting conditions; others are unable to qualify for well-paying jobs. For these individuals, Medicaid becomes the only option for health care coverage.

While there are state-to-state variations, individuals with assets of as little as $2,000 may be excluded from Medicaid coverage. Unless these laws change, parents who hope to provide financially for their child and ensure that he or she will receive adequate health care must find ways to avoid conflicts with Medicaid eligibility rules.

Trusts

Some type of trust is typically the best way to manage property for the benefit of a person with a disability, because the trustee (the person designated by the will to manage the trust) can be given the necessary discretion and flexibility to cope with the beneficiary's special circumstances. However, most trusts are considered "resources" under Medicaid regulations, which state that "resources are considered available both when actually available and when the applicant or recipient has a legal interest in a liquidated sum and has the legal ability to make such a sum available for support and maintenance."

To prevent governmental claims for reimbursement of benefits paid to the individual with a disability, and to prevent the individual from being disqualified from receiving government benefits, a trust established for the benefit of a person with a disability must be set up in such a way as to avoid being considered a resource. The language used in drafting such a trust is essential; for this reason, it is crucial to find an attorney who has experience in estate planning for children and adults with disabilities. (For more information on finding an appropriate attorney, see "Estate Planning: Getting Started," December 1995.)

In this column, attorney Frank L. Brunetti answers questions about any aspect of estate planning involving a child with a disability. Mr. Brunetti, a Professor of Law and Taxation at Fairleigh Dickinson University in Teaneck, New Jersey, has written extensively on the topic of estate planning for families who have children with disabilities.

Send questions to: Estate Planning, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742 (fax).

The community trust

"Community trusts," which are nonprofit organizations that pool resources for the benefit of people with severe disabilities, may be an option for some families. Community trusts address two major concerns for parents of children with disabilities—preservation of assets and selection of a knowledgeable trustee. A community trust ensures that a beneficiary's interest in the trust will not be considered a resource and protects that interest against claims by creditors. In return for contributions to a community trust, a designated individual with severe disabilities can receive lifelong services such as trust fund administration, advocacy (for example, participation by community trust representatives in the development of individualized service plans) and/or guardianship.

Currently, only certain states allow the establishment of community trusts. Furthermore, because these trusts are a relatively new concept, we have no long-term data on their success.

The special needs trust

A "special needs trust" (SNT) gives the trustee absolute discretion to spend trust assets for expenditures that are not covered by public assistance programs. In an SNT, income and principal are alternately used to pay for supplemental or "extra" items that will enhance the beneficiary's quality of life—vacations and field trips, traveling companions, entertainment, medical and dental treatments that are not otherwise covered, social services and transportation. In essence, the SNT is a backup fund intended to supplement, *but not replace*, public assistance. Thus, care should be taken to prohibit the trustee from spending trust assets on necessities such as food, clothing or shelter—all of which are currently covered by government assistance programs.

The SNT must be carefully drafted to prevent governmental claims for reimbursement of benefits already paid to the beneficiary, and to prevent the beneficiary's disqualification from receiving future benefits. In addition, the parents' will should provide for an alternate plan to deal with a governmental attempt to "break" the trust (by bringing a lawsuit against the trustee in an effort to force trust assets to be treated as "resources"). In that event, for example, the trustee may be directed to terminate the trust and distribute its proceeds to other relatives, if any, or to an alternate beneficiary (an individual, private foundation or community trust, if one is available) who will use the funds in the best interests of the beneficiary.

Other considerations in drafting the SNT

The SNT can also require the trustee or another person to make periodic evaluations of the beneficiary's care and

needs, including evaluations of facilities where the individual lives or receives treatment. The trustee may also be required to consult state and federal agencies to ensure that the beneficiary is receiving all the benefits to which he or she is entitled.

Most SNTs should also include a "spendthrift clause," which prohibits the beneficiary from selling or giving away his or her interest in the trust. In most cases, this clause will also protect trust assets against claims by creditors.

Finally, it is essential that the SNT provide for dispersal of trust assets following the beneficiary's death. Even if there are no surviving relatives, the estate planner must designate a final repository for trust assets. Parents may consider empowering the trustee to make distributions to a community trust, should that option become available. But in no case should trust assets pass to the beneficiary's estate because this would make the assets liable to claims by creditors. **EP**

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Circle #102

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Children's Specialized Hospital

Circle #63

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Circle #107

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WHAT'S HAPPENING

DO-IT! Scholars Program Applications Available

DO-IT (Disabilities, Opportunities, Internetworking and Technology) is a program that allows students with disabilities, who have an interest in pursuing a career in science, engineering or mathematics, to further explore their interests. The program includes internetworking, in which students learn to use computers and communicate via the Internet, and mentoring, in which students work with each other and with engineers, scientists and faculty—many of whom also have disabilities. DO-IT is sponsored by the University of Washington and funded by the National Science Foundation. Students in their sophomore and junior years of high school are encouraged to apply for this year's program by the end of February. High school freshman may apply for admission to next year's program. For more information and an application, contact DO-IT, University of Washington, 4515 15th Ave. N.E., Rm. 206, Seattle, WA 98105-4527, (206) 685-DOIT, voice/TTY; (206) 685-4045, fax; email: doit@u.washington.edu.

Free Braille Publication

Expectations is an annual anthology of children's literature in Braille, for grades three to six. This free publication includes color illustrations with raised edges and a "scratch and sniff" page. Included with each copy is a 1996 calendar printed in both Braille and large print. Contact the Braille Institute Sight Center, Communications Dept., 741 N. Vermont Ave., Los Angeles, CA 90029, (213) 663-1111 ext. 371.

Coming in October 1996 EXCEPTIONAL PARENT at Disney World AND YOU'RE INVITED!!

Encouraged by your responses to the note in *Editor's Desk* in the October 1995 issue, we are beginning to plan for a fun family trip to Walt Disney World in Orlando, Florida, in late October, 1996, as part of our 25th Anniversary celebration. We want as many of our readers and their families as possible to join us.

We are planning this exciting event in collaboration with the experts in travel planning for individuals with disabilities at AccessAbility Travel, a division of FPT Travel Management Group, Cambridge, Massachusetts. To move ahead with our plans, we need to hear from readers who are very interested in participating; and we need information about the special needs of your family members.

EXCEPTIONAL PARENT Disney World Survey

Interested? Please complete this survey and return it at once, or call (800) 382-0206 (voice) or (800) 228-5378 (TTY) to express your interest. Based on your input, we will plan our itinerary and keep you informed on the pages of the magazine. Please be assured that completing this survey does not obligate you in any way. To discuss your ideas and questions, please contact Judith Perry, director, EXCEPTIONAL PARENT Disney World Celebration, AccessAbility Travel, 186 Alewife Brook Pkwy., Cambridge, MA 02138-1102; (800) 382-0206 (voice), (800) 228-5378 (TTY), (617) 661-3354 (fax); jap@fpt.com (e-mail).

Name (please print) _____

Mailing address (please print) _____

City _____ State _____ Zip _____

❑ Yes, we want to join the celebration at Disney World in Orlando in October

Our group will include: _____adults _____children

Special needs (please check)

❑ transportation (to and from events)

❑ van rental ❑ auto rental ❑ regular bus ❑ special bus

❑ mobility

❑ manual wheelchair, stroller ❑ power chair ❑ wheelchair maintenance & repair

❑ sign language interpreter

❑ special medical technology

❑ respirator ❑ ventilator ❑ other (please describe)_____

❑ incontinence ❑ need special bed (please describe)_____

❑ special seating needs (please describe)_____

❑ special eating needs (please describe)_____

❑ other special needs (please describe)_____

Besides Disney World, we are also interested in enjoying the following attractions:

❑ Sea World ❑ Universal Studios ❑ Wet N' Wild

Your suggestions _____

On the list below, check those activities that would be of interest to you and your family:

❑ networking opportunities for parents ❑ educational programs for parents

❑ meeting with EXCEPTIONAL PARENT staff members ❑ programs for siblings

❑ adaptive sports ❑ organized social programs for children/ teens

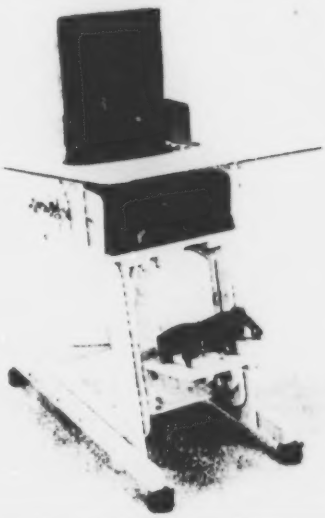
❑ exhibits of adaptive mobility equipment ❑ exhibits of computer equipment

206

The *New* LeisTech Positioning Chair!

Tired of the institutional looking positioning chair?

Take a look at this finely crafted piece of furniture.



The LeisTech chair correctly and comfortably positions the involved child for both classroom and home activities. Allows for years of growth and is easy to adjust. Available with a tilt in space option, and custom modifications to meet the needs of each child.

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Use of Safety Helmet Required

Circle #173

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Appealing a Denied Claim

Q My nine-year-old son has Duchenne muscular dystrophy. He has immediate need of a new power wheelchair. His present chair is too small and is aggravating the contractures of his leg muscles (shortening of muscles resulting in stiffness).

I have been verbally denied coverage for the wheelchair based on the first round of letters we have sent to the insurer. We are now appealing with letters from three doctors. One letter is cosigned by a physical therapist. If you can help, I would appreciate it.

A Unless your insurance policy specifically excludes or limits coverage for durable medical equipment, or equipment for children with specific disabilities, a power wheelchair is usually considered a covered item.

However, insurance policies provide coverage only for equipment that is "medically necessary." Supporting documentation, such as a doctor's letter, is often required to demonstrate medical need for the equipment.

The number of letters sent with a claim appeal is not as important as their content. First, the letters must be signed by a physician. Second, although requirements differ from insurance company to insurance company, the letters must include specific information about the child's medical condition.

The letters you include with your claim appeal need to explain why your son needs a wheelchair and why he cannot use a manual wheelchair. That information may already be on file with the insurance company as a result of prior claims, but it should be noted again. Since the claim is for a replacement wheelchair, the letters should also explain why your son's current wheelchair no longer meets his medical needs. If your son's need for a new chair is related primarily to his height and weight, the letters should include information about his size.

It is important to talk with your son's physical therapist and a medical equipment professional (who also may be called a "rehabilitation and technology supplier" or "dealer," since he or she sells equipment). These professionals can recommend the specific power wheelchair most appropriate for your son. They can also describe the accessories—specialized switches or controls, special seats and/or cushions, special arm or leg rests—that your son may need with the wheelchair. These accessories, which can be quite expensive, may be covered by the insurance policy if purchased with the wheelchair, but may *not* be covered if purchased later, as separate items.

By necessity, medical equipment suppliers have developed considerable expertise on preparing written documentation for specific local health insurance companies and are likely to have specific suggestions for how such requests should be phrased. It can also be helpful to obtain a cost estimate for the wheelchair and accessories from the wheelchair supplier; include that information with your claim appeal. This allows the insurer to consider approving a claim for a specific wheelchair, rather than just reviewing a general request.

Once everyone agrees on the type of power wheelchair and accessories your son needs, discuss these recommendations with your son's doctor. Ask the doctor to include the specific name and/or type of wheelchair and accessories in his letter to the insurance company.

Some insurers have detailed rules and procedures for the purchase of expensive medical equipment. Be sure to check with your insurer about those rules before purchasing the wheelchair. If the insurer does approve the claim, obtain that approval in writing.

Given your son's age, he is likely to need additional room in his wheelchair as he continues to grow. Ask your son's doctor, physical therapist and wheelchair dealer whether a wheelchair seat that can be adjusted to accommodate a growing child may help solve that problem. Such seats are designed as a replacement for the standard wheelchair seat and fit on many power chairs. If the clinical team feels that this seat is appropriate for your son's current and future needs, find out whether your insurance company will pay for it. If so, this type of seat may allow you to extend the time before a new wheelchair becomes necessary. **EP**

EDITOR'S NOTE: The Muscular Dystrophy Association (3300 E. Sunrise Dr., Tucson, AZ 85718-3208; 800/572-1717) provides financial assistance for the purchase of mobility equipment for children with Duchenne and other muscular dystrophies.

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

NEW PRODUCTS

THE SPECIAL NEEDS 3

The Special Needs 3 allows parents of older children with disabilities to take their children walking or jogging in comfort. The stroller accommodates children weighing up to 150 pounds and can be used on unpaved trails, even in mud, snow and sand. Its sleek design and a choice of seven bright upholstery colors give the stroller a non-orthopedic appearance. Features include padding under the seat and on the push-handle, a folding frame for transport and storage, and a choice of 16- or 20-inch quick-release wheels. Custom modifications are available.

Racing Strollers, Inc., Yakima, WA 98907

Circle #294

LORE ALPHABET PLAYING CARDS

Lore Alphabet Playing Cards offer a fun way to encourage hand-eye coordination and simple reasoning skills; they also reinforce letter recognition, phonics and word-building skills. The deck contains four cards for each letter of the alphabet. Each card is illustrated with a large, blue letter and one of four suits—diamond, dot, star or triangle. The card set includes a carrying case and activity book with instructions for more than a dozen letter and word games.

Lore Playing Cards, Baltimore, MD 21209

Circle #295

THE BOWLING BUDDY

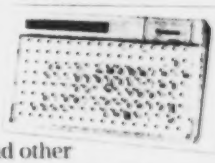
The Bowling Buddy gives power wheelchair users full control of their bowling games. Two hand-adjustable clamps attach the unit to any power wheelchair frame, and thumb screws allow adjustments to the ball holder and guide. Manipulation of the wheelchair's joystick determines the spin on the bowling ball, and the wheelchair's momentum determines the ball's speed. The push-arm flips up so wheelchairs do not have to remain stationary while the unit is in use. The Bowling Buddy divides into two sections for easy transport and storage.

The Creative Shop, Leoma, TN 38468

Circle #296

UNITY/128

Unity/128, a new vocabulary program for use with Prentke Romich's Liberator and DeltaTalker communication devices, features a series of four 128-location overlays. The overlays include pre-selected vocabulary and icons, and they offer, in succession, an increasing number of vocabulary and grammar options—from 78 common single words to 2,000 word roots that can be modified to reflect tenses, pluralization and other grammatical changes. Unity/128 grows with its users and adapts to their changing needs, minimizing the need to unlearn and relearn new programs. With the program's large, single-word vocabulary, users can develop categorization and association skills, practice using language in everyday situations and generate original sentences.



Prentke Romich Company, Wooster, OH 44691

Circle #297

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Sta-Mat for Kids helps keep kids and their activities in place. This portable mat makes any surface non-slip. Use it to keep children from sliding down in their seats or to hold plates, cups, toys or projects in place. Sta-Mat is non-toxic and safe for any surface. The mats come in red or blue 12 x 6 inch rectangles that can be trimmed to any size or shape.

Sta-Mat for Kids, Arvada, CO 80001-1438

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Exploring Concepts, Wilmington, NC 28401

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT*'s "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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ASK THE DOCTOR

by David Hirsch, M.D.

Hyperextension and Arching; Crying Outbursts

Q Our 15-month-old daughter has spastic quadriplegia (severe spasticity of all four extremities), a seizure disorder, cognitive delays and a cortical visual impairment (meaning that her brain cannot process visual images).

As she gets older, it is becoming increasingly difficult to hold and position her. This is because she constantly hyperextends her body and arches her back. She cannot sit unsupported for longer than a few seconds because she constantly throws herself back. When we try to hold her, she usually arches back, forcing us to lay her down.

What causes this? Is it a reflex caused by excessive muscle tone or a behavior she can control? Does it get better?

A Unfortunately, this is a common problem in children with spastic quadriplegia. In my experience, it is more common in children with spastic quadriplegia who also have visual problems. I believe this behavior often occurs as overreaction to environmental stimuli.

Your daughter probably cannot control this behavior and may literally exhaust herself with the arching. Her increased muscle tone just makes things worse; in fact, the tone may cause further discomfort when she arches, which she might react to with further arching and hyperextension of her body (a type of vicious cycle).

Some pediatric neurologists believe that the beginning of some of these episodes may actually be seizures. Has your daughter had a recent EEG? Are her seizures under control?

I have also seen children in whom gastroesophageal reflux (severe heartburn) and even constipation have caused similar episodes. In such cases, the reflux or constipation may not be severe enough to cause more the obvious symptoms that would lead to further medical evaluation.

I think you should also consider any medications your daughter is taking on a regular basis. They could be causing stomach upset. You should also look at her diet. She may be reacting in an atypical manner to a food in her diet. Does your daughter have a gastrostomy (a surgically-created opening in the abdominal wall for a feeding tube)? Sometimes a gastrostomy can cause irritation.

Physical therapy to help decrease your daughter's muscle tone is important and very useful, but it is a long-term approach. In the short term, you might experiment with various positioning maneuvers such as placing your daughter in a side-lying position with rolled-up towels behind her back or gently bending one leg forward from the hip. These maneuvers will often stop the reflex that starts the vicious cycle of arching and hyperextension. Gently rocking her in her adaptive seat may also be helpful. When riding in the car, try to make sure your daughter's head is facing forward and that her car seat's pelvic seat belt is fastened snugly.

Muscle relaxants may be another short-term approach. I have used such drugs as Tranzene (clorazepate), among others, with some success, in conjunction with physical therapy.

In my experience, if all possible medical causes have been ruled out or treated, this difficult problem does seem to improve somewhat with time and therapy.

Q For the past seven months, our three-year-old son has been having crying outbursts that last from five to 10 minutes. These outbursts occur both day and night; he even cries in his sleep. Our son has cerebral palsy, a seizure disorder, hydrocephalus (with a shunt), severe developmental delays and a visual impairment. I have taken him to his pediatrician, neurosurgeon, neurologist and even the dentist. He's had a variety of tests including MRIs and CAT scans, EEGs, x-rays and blood work. Doctors have checked the blood levels of his anticonvulsant medication. Because he becomes very constipated, we have even given him enemas. Months later we still have no explanations.

These outbursts typically begin with him shaking his head from side to side. Then he closes his eyes tightly, and his right arm goes up and down until the crying stops. Doctors keep telling us he is okay, but we believe he is in pain. His constant crying breaks our hearts because we have no way to help him.

A I agree that something is bothering your child. The "outbursts" you describe sound like they may be a type of seizure or seizure-like activity. You mentioned a number of tests that have been done. Although these tests may not have suggested seizure activity, such results do not *always* mean a seizure is not occurring. I also assume that any problem related to his hydrocephalus or shunt have been ruled out. Unfortunately, children with central nervous system impairments similar to your son's often cannot control an overreaction to pain or environmental stimuli; this type of overreaction could also cause the behavior you describe. The best solution is to try to find any source of pain or irritation.

Several types of physical problems can cause the behav-

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT'S *Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: **Ask the Doctor,** EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (fax).*

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[redacted]

for you describe. One of the most common is constipation, a frequent cause of "unexplained" discomfort, especially in young or nonverbal children. The fact that you are giving your son enemas does not mean that he is not having abdominal pain related to constipation or excess gas. Have doctors done an abdominal x-ray to be sure he is not still constipated? Gastroesophogeal reflux (severe heartburn) may also be a cause of pain. Certain x-ray studies or other tests arranged by your son's doctor can rule this out.

If any of his medications are bothering him, he may respond by crying. Does there seem to be any relationship between administration of his medications and his crying outbursts? If so, ask your son's doctor if you can safely skip a dose of the medication every other day to see if his crying spells disappear on the days he is off the medication.

Frustration stemming from an inability to communicate can also cause unexplained behavioral problems, but, since your son's crying also occurs when he appears to be sleeping, this is probably not the cause of his outbursts. In addition, such behavioral reactions are more commonly seen in children who are a bit older than your son.

I wish I could be of more help. I feel you need to bring your son back to his pediatrician for a reevaluation of his crying episodes. You may also want to talk with your son's physical therapist to see if he or she has any suggestions for keeping him more comfortable. **EP**

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by Ayala Manolson, M.Sc., CCC

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EDITORIAL INFORMATION: Contact Dr. Stanley Klein. *Exceptional Parent*, 209 Harvard Street, Suite 303, Brookline MA 02146-5005. Return postage must accompany all manuscripts, drawings and photographs submitted. Publisher assumes no responsibility for unsolicited material.

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EXCEPTIONAL PARENT

February 1996

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B. Are you the PARENT or MEMBER OF THE FAMILY of a child or young adult with a disability or special health care need? 1☐ Yes 2☐ No

C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3☐ Yes 4☐ No

If Yes, are you a: 5☐ Physician 6☐ RN 7☐ Physical Therapist 8☐ Occupational Therapist 9☐ Speech Pathologist; Audiologist 10☐ Other (please indicate) _____

D. Are you an EDUCATOR? 11☐ Yes 12☐ No

If Yes, are you a: 13☐ Special Ed Teacher 14☐ Regular Ed Teacher 15☐ Admin/Dir. 16☐ Other (please indicate) _____

E. Do you buy or influence the purchase of products or services for the care or development of children with disabilities? 17☐ Yes 18☐ No

If yes, please explain _____

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F. Have you ever bought or recommended a product or service you saw advertised in *Exceptional Parent*? 19☐ Yes 20☐ No

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C. Are you a HEALTH CARE PROFESSIONAL involved in the care of children or young adults with disabilities or special health care needs? 3☐ Yes 4☐ No

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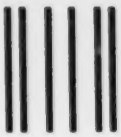

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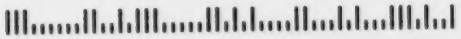

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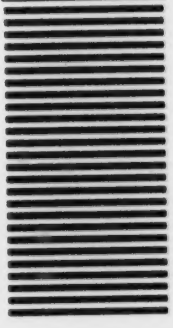

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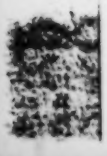

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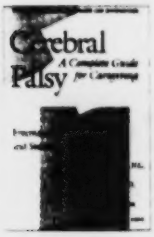

Written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute in Wilmington, Delaware, CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING addresses the many complexities and uncertainties related to this diagnosis. At the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications to wheelchair maintenance and dental care. The book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt.

Toilet Training Your Child

The most important factor in successful toilet training is the attitude of the parent, who must be relaxed and positive about the process of toilet training and who must convey this attitude to the child.

Praising the child for success on the potty is crucial. But even before toilet training can begin, both the child and the parent must be ready. Your child may signal her readiness for toilet training in one of several ways. For example, while urinating or having a bowel movement (or just before), the child may become either fussy or quiet, wiggle and demonstrate the need to change position, suddenly lie or stand very still, go to the corner and squat, change facial expression or say that she is wet. The parent needs to pay attention to these behavioral changes and be ready to interpret these gestures to mean that the child needs to eliminate. Only when all these signals and good intentions come together can toilet training begin in earnest.

ESTABLISHING A PATTERN

One thing that will help establish a pattern of elimination is keeping regular mealtimes. In this way, the stomach, bowels and bladder will be empty and full at regular intervals. Not only that, but food tends to stimulate the bowel, and many people go to the bathroom after a meal—usually breakfast or dinner—so you may be able to predict your child's bowel habits based upon mealtimes. After you've determined the normal pattern of elimination, you'll know when to place your child on the toilet in order to achieve the best success.

GETTING STARTED

Choose a time when your child is rested and in a good mood to begin. You'll need a child-size potty chair or potty seat.

When your child has indicated (by one of the above gestures, or something similar) that she needs to urinate or have a bowel movement, take her to the bathroom and explain in simple language what is to be done. Use very specific common words to describe the act of elimination. Place the child on the seat and stay with her until the training session is completed. After about five minutes on the toilet, the child should be wiped and rewarded with hugs and praise for the desired behaviors.

If the child was not successful in achieving the desired behavior, praise her for cooperating and sitting quietly on the toilet or potty chair. During training, the child should sit on the seat without toys or playthings, since these would divert attention from what she is supposed to be doing.

Repeat this process until the child is able to tell you in advance that she needs to go, or is able to use the bathroom or potty on her own.

BOWEL TRAINING

If your child is mentally retarded, it may be helpful to institute a bowel training program. This, too, involves establishing a regular pattern of meal times to help establish a regular pattern of elimination, but the difference is that routinely, about 15 to 30 minutes after one meal is finished, the child is placed on the toilet for 15 to 30 minutes. Choose either breakfast or dinner and stick with it, since the point of a bowel training program is to train the child to produce a bowel movement at the same time every day or every other day.

Make sure that the child is comfortable, with feet flat on the floor or supported by a stool. Use simple descriptive common words to describe the desired activity. Again, be positive by praising the desired results, and praise the child for sitting on the toilet as you wished, even if there is no bowel movement. Be sure there are no distractions during this time.

If the child does not produce a bowel movement after two days, give him an enema. Put him on the toilet every day at the same time after the same meal, and allow only one day to go by without a bowel movement. That is, if the child doesn't have a bowel movement one day, he should have one the next day, either on his own or by having an enema.

Continue this routine until the child is trained.

ADAPTIVE TOILETING

Special handling techniques are used for toileting the child with cerebral palsy who is physically challenged. To protect the child (as well as themselves) from injury, care providers need to learn these techniques. Ask a physical or an occupational therapist for tips in handling your specific child. **EP**

Excerpted from CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING by Freeman Miller, M.D. and Steven J. Bachrach, M.D. (with Marilyn L. Boos, R.N., Linda Duffy, P.A.-C., Douglas T. Pearson, Ph.D., Rhonda S. Walter, M.D. and Joan Lovett Whinston). Published by The Johns Hopkins University Press, 1995.

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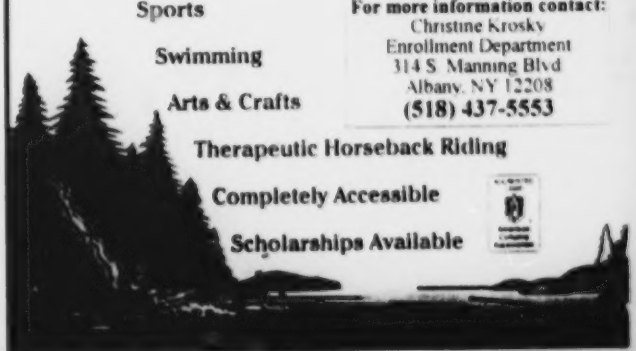

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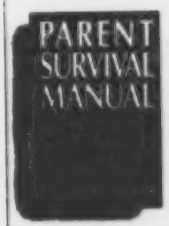

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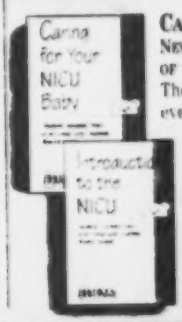

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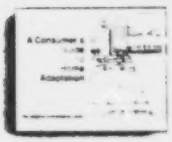

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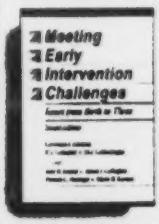

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My Next Door Neighbor

By Kathleen Gove

My next door neighbor is Elizabeth Nolan. She has Down syndrome. Down syndrome is when a person is born to be slow. Elizabeth is a really good friend, but some kids don't like her because of the Down syndrome. So I play with her. Elizabeth's mom is really nice, too. And her sister, Trish, is a really good basketball player—she is in the newspaper a lot. Elizabeth is my best friend, and she is like a sister to me! **EP**

After a summer morning spent running through the sprinkler, Kathleen gives her buddy, Elizabeth, a squeeze.

Best friends!

Kathleen Gove, 10, lives with her parents, Diane and Bob, and her sister Colleen, 14, in Wilmington, Delaware. A fourth grader at the P.S. DuPont Middle School in Wilmington, Kathleen wrote this piece as a school assignment when she was in the third grade. Kathleen loves soccer, basketball and softball almost as much as she loves spending time with her best friend, Elizabeth Nolan, 9, who attends the Wilmington Montessori School. The two girls have been friends for six years.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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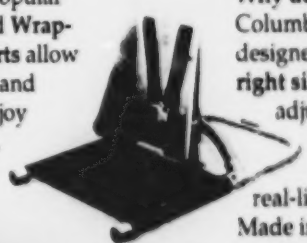

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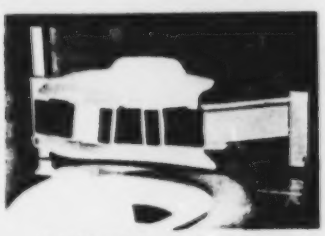

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Cover: Melissa Nicholson, 9, and her brother, Chris, 11, check out the toy department of the North Aurora, Illinois Kmart store, using Melissa's scooter basket as a shopping cart. Described by her parents as a "natural driver," Melissa, who has achondroplasia, enjoys the mobility her scooter provides—especially at the mall!

Melissa and Chris live with their parents, Mike and Debbie, in North Aurora, Illinois. Both children attend Schneider Elementary School, where Melissa is in the third grade and Chris is in the fifth. Photo: Carlos Vergara/Carlos Vergara Photography.

Special thanks to Kmart, Debbie Koerber of Denson Shops, Inc. and Bruno Independent Living Aids for their help in arranging this photo.

BPA

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EDITOR'S DESK

Seventh Annual Mobility Issue

To prepare this year's Mobility issue, we hosted a telephone roundtable discussion among mobility experts. Although we began by focusing on mobility-related issues, the conversation soon turned to more general concerns—empowering parents to play an equal role in the decision-making process, sharing information among members of the child's team and admiting needs without placing blame. The end result was an article full of useful information for parents and professionals who are dealing with mobility issues—and for all those navigating the day-to-day challenges of parenting and advocating for children with disabilities.

STANLEY D. KLEIN, PH.D.

More on managed care

At NORD's (National Organization on Rare Disorders) annual conference last fall, David Hirsch—our *Ask the Doctor* columnist—discussed how his private group practice had handled Arizona Medicaid's shift to a managed care model. To continue caring for young patients with disabilities and special health care needs as primary care pediatricians, Dr. Hirsch and his colleagues had to show Medicaid and other third-party payers why these children and their parents require additional services. I invited Dr. Hirsch to prepare an article about his experiences ("Children with Special Health Care Needs and Managed Care") so our readers could learn that there are creative ways for health care providers to deliver good care within managed care.

In February, I attended a conference on managed and long-term care for people with developmental disabilities. Speakers at this conference, sponsored by the American Association on Mental Retardation (AAMR), reported on a number of collaborative efforts in which professionals, parents and consumers are working together to make sure managed care meets both health care and supportive living needs for people with disabilities. Many presenters at this meeting have accepted my invitation to share these stories with us in coming months.

At the same time, our *Letters* department includes several responses to our December 1995 article on managed care. Clearly, many problems remain.

Blaming parents

Twenty-five years ago, when we published the first issue of EXCEPTIONAL PARENT, parents were routinely blamed for their children's problems—no matter what those problems were. In recent years, this blaming has greatly decreased. But now it seems to have appeared in a new form. An article by Teresa Wolding ("So… Why Was *Your* Baby Born Early?") offers powerful examples of the unanticipated results of well-intentioned public education efforts. We appreciate the March of Dimes' response to Wolding's article and also welcome the input of readers and other organizations.

25th anniversary celebration

We have already received many responses to our plan for a special family celebration at Walt Disney World this fall. We hope many readers can join us. To let us know of your interest, please send in the form on page 90.

Summer camp

In 1995, I had the opportunity to visit Camp CAMP in San Antonio, Texas, a program that is unique not only because it provides an exciting and enjoyable camping experience for children with complicated health care needs (and their siblings), but also because it serves as a resource for training health care professionals. There are many fine camps, and this story illustrates the fine purposes a camp setting can serve.

Corporate Awards

Beginning in this issue, in collaboration with the National Organization on Disability, we honor corporations that are providing employment opportunities to people with disabilities, supporting the participation of these employees in everyday corporate life and featuring people with disabilities in advertising programs. We congratulate our first award winner—AT&T.

EXCEPTIONAL PARENT

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For subscription and advertising information, see page 92

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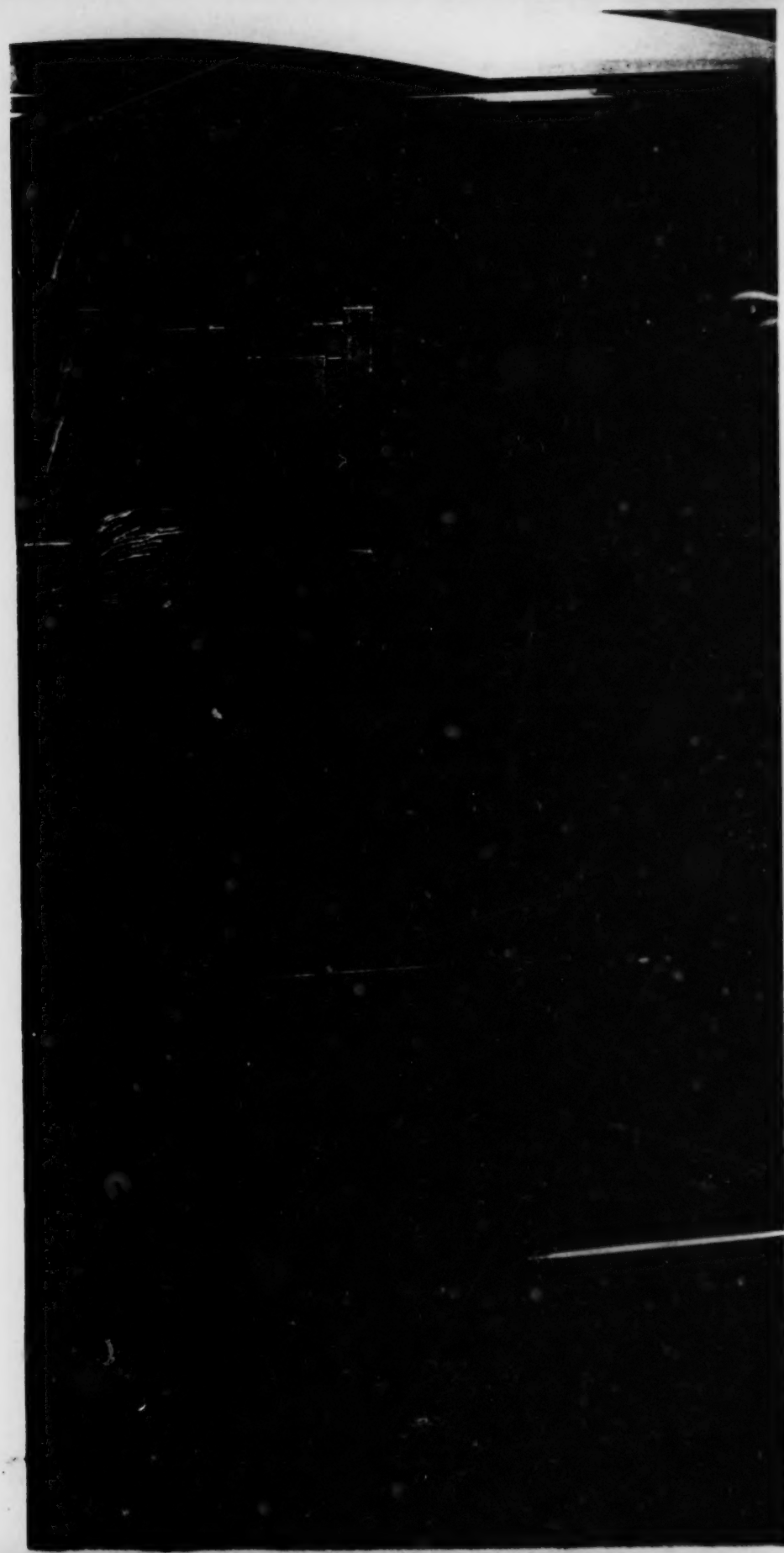

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LETTERS

Managed Care

I am the father of a five-year-old daughter, born with a 7;9 chromosome translocation, who has cognitive and physical disabilities. She receives gastrostomy feedings, and has a cleft palate, spastic quadriparesis, neurogenic bladder, sleep apnea and a seizure disorder. She receives physical, occupational and speech therapies, as well as 24-hour-a-day nursing in our home.

For the last five years, my daughter's medical expenses have been fully covered by my wife's insurance company (Aetna Indemnity policy). Every year Aetna tried to cut back on coverage, but through "letter wars" and reviews done by independent nursing companies, we always managed to retain all services.

In October 1995, my wife's employer announced that the company's insurance plan would be changing to Aetna's Managed Care policy. She was told that limitations of this new policy would affect our daughter; for example, the policy covered only 800 hours of in-home nursing a year, and only 90 days of physical, occupational and speech therapies. The case manager, however, told us that Aetna would call a meeting with the two insurance companies in an attempt to maintain our daughter's services.

But after several letters and many, many phone calls, we still worried that we would be left without nursing or therapies after the 90-day transition period; and neither insurance company made any attempt to reassure us that this would not be the case. In order to obtain another year of indemnity coverage for our daughter—due to extension of benefits through COBRA—my wife was forced to quit her job in the last week of December 1995.

The article about managed care infuriated me! After all, my wife, a senior executive for a mid-sized nationwide company, was forced to quit her job just to maintain another year of appropriate insurance coverage for our daughter. Managed care *cannot work* for children with special health care needs like our daughter!

Another problem with managed care is the quality of doctors in the plans. For example, the Cigna Managed Care policy available through my employer includes *none* of my daughter's specialists. A few of them participate in Aetna's Managed Care plan, but all have told me they plan to end their affiliation with that plan because they are losing money. What kinds of doctors stay with these plans? Are they doctors who would know how to care for a medically complex child such as my daughter?

I cannot see any advantages of managed care plans for children with special needs. Instead, managed care has created a huge dilemma for children who need timely and consistent specialized care. My concerns grow larger as my daughter's indemnity policy runs out.

T.M., New York

■ The authors of "Questions and Answers About Managed Care" (December 1995) infer that managed care is a positive choice for children with disabilities. I could not disagree more strongly and am concerned that this article will mislead parents into making detrimental choices.

My experience, as the director of the largest outpatient pediatric rehabilitation department in New Jersey, has been that families profit from none of managed care's potential benefits and suffer severely from its implementation. In theory, it may be a good idea; as practiced, it is simply a system of cost containment. Currently, its benefits accrue only to the insurers.

continued on page 5

EXCEPTIONAL PARENT

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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LETTERS

continued from page 4

The impact of managed care on families of children with disabilities and chronic illnesses—the families we serve—has been terrible. Rather than "managing care," companies are *denying care* or *limiting care* to totally inadequate levels.

The notion of designing treatment to fit the child and not the insurance policy is no longer feasible. We've seen a dramatic decline in the number of children whose policies cover needed therapies. If coverage exists, it is limited to 60 days or some such ridiculously inadequate and arbitrarily predetermined amount. Two- and three-year-old children, who have conditions such as cancer and cerebral palsy, are reaching their lifetime maximums.

In general, under managed care, only those children who have lost a previously-attained ability due to illness or injury are eligible to receive physical, occupational or speech therapy. Disabilities including Down syndrome, cerebral palsy and spina bifida do not meet the criteria for illness or injury. Birth defects are considered "pre-existing conditions," with the result that coverage for rehabilitation services is denied. The notion of managed care being an interactive system between case manager and patient/provider is just that—a notion. Decisions of the case manager are unilateral and non-negotiable.

I urge readers to be informed consumers who investigate what managed care will provide for their child. Family Voices, the group that authored "Questions and Answers About Managed Care," purports to represent the best interests of families of children with disabilities. Based on my experience, I can only wonder whether they have done their homework before presenting such a positive picture of managed care.

Patricia Munday, Director
Pediatric Rehabilitation Department
JFK Johnson Rehab. Institute
Edison, New Jersey

FAMILY VOICES RESPONDS: Family Voices is a national grassroots network of close to 10,000 families who have

continued on page 8

MOVE International

GIVING CHILDREN INDEPENDENT MOBILITY AND CHOICES

MARKUS SMITH
Working toward a dream

Markus' physical therapist, Darron Veh, called me in October of 1994. He wanted to "try something different" with my son. Markus is 10 years old and has cerebral palsy. We had "tried" many different things to improve his motor abilities, but Markus had made little progress in the last several years. Markus could stand in a prone stander, but hated it. He could wheel himself slowly and erratically in his wheelchair, but required assistance to travel any distance. His poor vision made motorized mobility risky. What type of experiment were we going to subject Markus to this time?

Darron introduced us to MOVE and the Gait Trainer and Mobile Stander. Markus loved the stander and was immediately able to wheel himself around in an upright position. Markus then tried the Gait Trainer. He struggled, but couldn't quite get it moving. As a team, we discussed which piece of equipment Markus should work with. We decided to work with the Gait Trainer because it would provide more room for improvement.

Markus initially required every prompt on the Gait Trainer and assistance to make it move. These struggles in the school hallways produced benefits far beyond the physical. Markus' schoolmates stopped to encourage him. A class of eighth graders gave him a spontaneous ovation. Teachers and students encouraged Markus and applauded his every little success. His self confidence began to grow.

A year ago, Markus told a doctor, "My greatest hope is to walk someday." He was now taking his first steps toward this dream.

After just four months, Markus is able to walk 30 to 40 minutes a day in his Gait Trainer, for distances of up to a half a mile. He now requires only the forearm supports and one leg prompt. He still has trouble controlling his direction, but the power is all his.

Markus has moved out of a wheelchair desk, and into a "regular" desk. He said, "I love having a desk like the other kids. I can get my own books and pencils and that other stuff." Even Markus' wheeled mobility has improved. His wheelchair speed has tripled, and he now wheels himself around the school completely independently.

My husband, Michael, has always felt Markus could walk if we could find the right equipment to give him the support he needed. We finally found the equipment and the approach. We look forward, with anticipation, to seeing what Markus can accomplish next.

–Gilda Smith, with Darron D. Veh

Markus Smith is a third grade student at Nickerson Elementary School in Nickerson, Kansas.

Darron D. Veh, P.T., is a physical therapist with Reno County Education Cooperative, which provides special education services to Nickerson Elementary School students.

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Apple

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children with special health care needs. Our article comes from one of many papers and bulletins written to provide our members, as well as policymakers, with objective information and informed guidance. The article defines and describes managed care, delineates some things to look for and provides a brief description of what might or might not work. The article was not intended to imply that managed care—especially as implemented by insurers like those described by T.M.—provides appropriate care for all children with special health care needs. The article does not say managed care improves the health status of our children, results in better care or even saves money.

Daily we hear stories about kids with special health care needs in managed care systems; some children have received good care, but many have not. With dozens of family leaders, we are now in the process of developing a list of health care criteria for children with special needs in managed care. We have also created and piloted a survey about family experiences with managed care. We hope our survey, written by families, will begin to provide baseline data about this important subject. For more information, contact Family Voices, P.O. Box 769, Algodones, NM 87001; (505) 867-2368; (505) 867-6517, fax.

EDITOR'S NOTE: For more on the topic of managed care, see "Children With Special Health Care Needs and Managed Care" on page 60.

Decisions in the NICU

Search and *Respond* are so wonderful. I can't tell you how many times I have cried while reading these letters, but it is uplifting to know how many people can really understand the pain, as well as the joy, that comes with having a child with a disability.

I recently had a *Search* letter published ("Unprepared," August 1995). I hoped to find parents with children similar to my son, Ian, who was born prematurely and had periventricular leukomalacia, a condition in which tissue around the brain's ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen. I am grateful for all the responses I received; however, these letters have made my husband and I increasingly concerned about the alarming number of preemies and micro-preemies with severe disabilities. It doesn't seem fair or even ethical to put so many children through all the NICU procedures, only to have them endure a lifetime of extreme disability. And with neonatologists saving babies weighing less and less, it seems likely that the number of children with disabilities will grow.

Many parents who wrote to us thought, just as we did, that everything would be fine once our babies came home from the hospital. In many of these cases, doctors seemed more interested in medical experimentation than in the life of the child or the quality of that life. When Ian was born 13 weeks premature and weighing only one and a half pounds, we asked that no extreme measures be taken to save his life. But doctors told us we did not have the right to make that decision!

Although words cannot describe how much I love my son, I question whether all these premature children should be saved. My husband and I hope to have another child, and we would like to know our rights when it comes to making these kinds of choices.

J.B., New Jersey

continued on page 10

Tell us about...

... balancing the demands of work and family.

Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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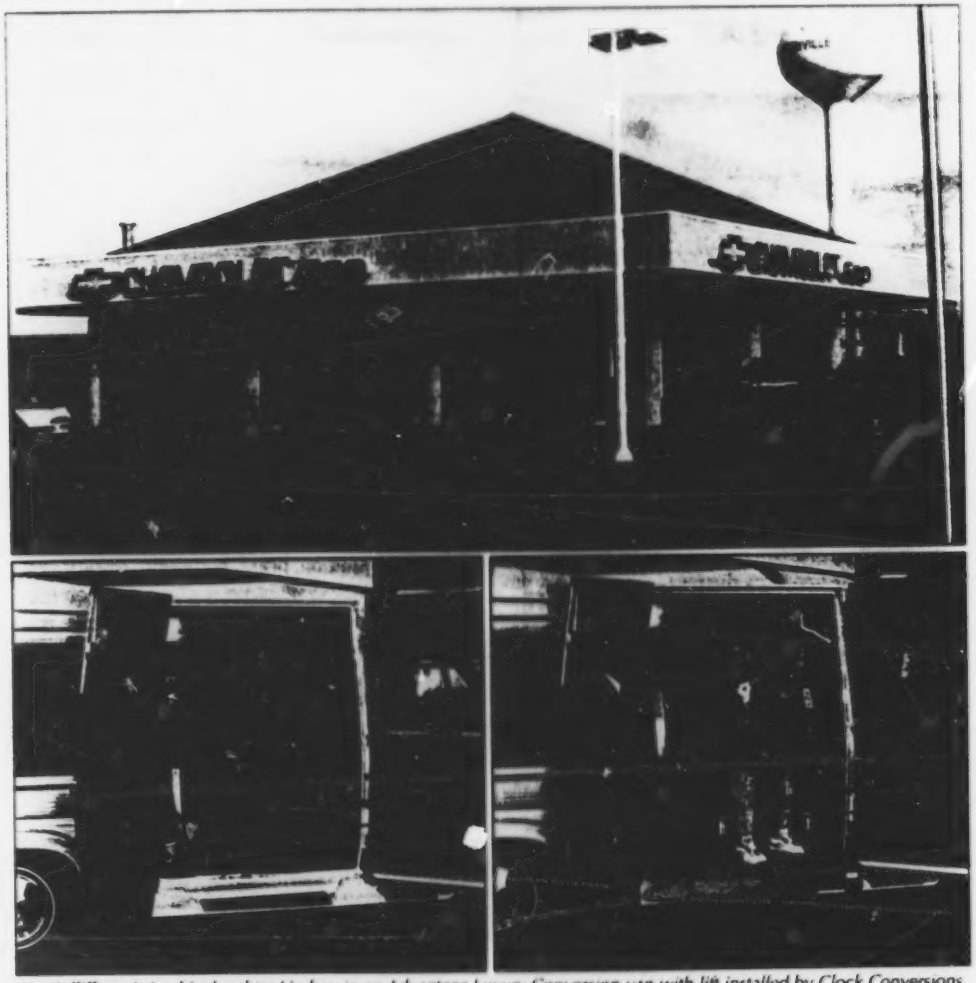

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continued from page 8

Respecting Choices

The letter from J.U. of California ("Respecting Choices," December 1995) was *right on* and well-spoken. I couldn't have said it better—inclusion is not appropriate for every child. My son has mental retardation and autism, and can only spend about 10 percent of each day in a regular first grade classroom. At first, this was difficult for me to accept. We all want our child to be included, but I realized my son wasn't learning in a room filled with so many other children. He learns so much more working in a smaller group in the special education classroom with occasional visits from the kids in his first grade class. This arrangement is working for him.

J.K., Minnesota

Special Olympics

Congratulations to you and your staff for the terrific June 1995 issue featuring the Special Olympics. I appreciate the time and consideration you gave this issue, and especially the article on the Special Olympics Unified Sports program.

I was greatly impressed to see copies of EXCEPTIONAL PARENT at all the family centers at the 1995 Special Olympics World Summer Games. I understand that you provided nearly 75,000 magazines to families, volunteers, coaches, athletes and spectators during the games. This was quite an undertaking, and we certainly appreciate your efforts.

It is a great service to parents to show, as you did, the abilities, sharing, pride, competitive spirit and caring for others that special athletes reveal to their grandparents, friends, and supporters. Again, my thanks and congratulations for a job well done.

Eunice Kennedy Shriver
Special Olympics International
Washington, DC

Parking Problem

I recently applied for and received a handicapped parking permit because my daughter, who has cerebral palsy, uses a pediatric wheelchair. On a recent trip to the mall, I discovered that all eight reserved parking spaces were taken. As I watched, one woman literally ran out of a department store and got into her car. Another vehicle parked in this reserved area belonged to two able-bodied workmen who were painting inside the mall. Another man, apparently healthy, strolled back to his car and loaded his packages. I was angry, but too embarrassed to say anything to these people.

What can be done about this problem? I'd love to hear some suggestions for a tactful way to confront those who obviously should not park in these reserved spaces. I do not want to offend anyone, especially if they are justified in using these parking areas, but I know I would not mind if someone questioned me, because I would never use handicapped parking unless my daughter was with me.

B.S., New York

EDITOR'S NOTE: See "New Parking Police," page 91, for a story about the innovative method the city of Austin, Texas is using to deal with this problem. We'd love to hear how other readers have dealt with this problem as well.

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Everyday Hero

RICON

A Great Scouting Opportunity.

Troop #767SNS (Special Needs Scouts) of Orange County, CA, is just like any other boy scout troop, except for one thing—every member has a disability. Because most of the boys use wheelchairs, their participation in traditional scouting activities is a major challenge...but one they face with pride and determination. The troop, founded by Bruce Marich, president of Southern California Mobility, is currently raising money to buy a mini-bus equipped with a Ricon lift.

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Circle #129

continued from page 10

Thanks!

Thanks for a *great* magazine. Three of my four adopted children have disabilities, including learning disabilities, mental retardation, attention deficit hyperactivity disorder (ADHD) and Gorlin-Goltz syndrome. My quite complex family requires a battery of specialists, therapists, counselors and special educators.

I spend a large amount of time at "assessments" and meetings, but find very little practical help. But the minute I get EXCEPTIONAL PARENT in the mail, I sit down with a cup of coffee and read it from cover to cover. The various stories inspire me and inform me, even though Australia's educational system differs greatly from that of the U.S.

L.C., Evatt, Australia

■ Just a note to say thanks and *great job!* I love EXCEPTIONAL PARENT. My first child, Kyle, has Down syndrome and a seizure disorder. After he was born, I did the usual thing new parents do—I subscribed to the usual baby magazines. But I soon realized these magazines were depressing me. They were full of articles about "normal development" and people living "normal" lives, and they didn't seem to have very much that pertained to us.

When my son had to spend a few weeks in the hospital, I borrowed a year's worth of EXCEPTIONAL PARENT magazines from a friend. During those three weeks, I read and read and read. I left the hospital with a subscription card in my hand and have enjoyed each issue ever since. Thanks!

P.S., Michigan

Environmental Controls

EXCEPTIONAL PARENT's November 1995 issue provided an excellent look into the ways technology is opening up new worlds for children with disabilities and their parents, especially through environmental controls and computer access.

Infrared technology allows DynaVox 2 users to turn on a computer and access on-line services—without needing cables.

One point that was overlooked, however, is that technology is being harnessed to provide more efficient, cost-effective tools for children and young adults with disabilities. For example, Sentient Systems' DynaVox 2/2c communication devices include *built-in* environmental controls that allow individuals to operate both appliances, such as TVs and VCRs, *and* personal computers.

Infrared technology, which is built into these devices, provides access to new ways of communicating—through the Internet and computer on-line services. These services provide many educational resources that users can access without assistance. As a result, they attain greater independence and self-esteem, which leads to better communication, learning and success—both in and out of the classroom.

Tilden Bennett, President
Sentient Systems Technology
Pittsburgh, Pennsylvania

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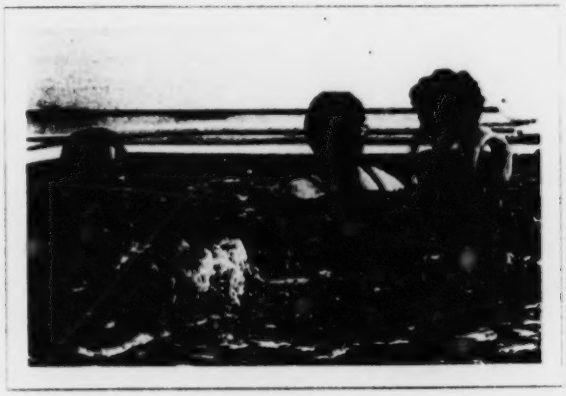
Berkshire Meadows



Nestled in the serene beauty of western Massachusetts' Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

Like other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.

The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

Weekends and holidays are for fun. We take full advantage of the loveliness of our natural surroundings, and of the receptive friendliness and extensive activities of local communities.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

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SEARCH

Spinning Objects

My two-and-a-half-year-old twin sons were born three months prematurely. By the time they were 18 months old, it was clear they were "developmentally delayed." They did not speak and were preoccupied with spinning objects, especially toy plates and cups. However, the professionals who evaluated them did not believe they had autism.

They attend an infant stimulation program and receive speech therapy. They seem to be making progress and are now beginning to talk. However, their interest in spinning objects has continued.

I'm not sure how to deal with this behavior. I've tried ignoring it, distracting them, and showing them more appropriate ways to play with toys. They do not only spin things; they *also* play with toys appropriately. Their developmental pediatrician told me, "Just let them spin things. They will grow out of it." But most of the other professionals working with the boys tell me I should try to intervene.

I just don't know what to do. I don't want this spinning thing to become habitual, but what sort of intervention will work? Can anyone help? Sometimes I feel very alone.

B.L., California

Trisomy 12p

Our nine-year-old son was diagnosed with trisomy 12p at birth. We have never been able to find another child with this diagnosis. Is there anybody out there?

B.F., Illinois

Dyggve-Melchior-Clausen syndrome

My 10-year-old son was recently diagnosed, after an eight year search, with Dyggve-Melchior-Clausen syndrome (DMC). Characteristics include short-trunk dwarfism, microcephaly, scoliosis, restricted joint mobility, dislocated hips and mental retardation. DMC is very rare, with only about 50 documented cases worldwide. (Another type of short-trunk dwarfism, Smith-McCort dwarfism, has all the features of DMC except mental retardation). Doctors initially thought Jason had one of the mucopolysaccharidoses, however, this type of metabolic disorder was ruled out by blood and urine tests.

Jason's short neck puts him at serious risk of spinal cord injury. Our doctors are already suggesting a spinal fusion, which would involve the "halo type" operation and more than four months of slow recovery. Because of his

continued on page 16

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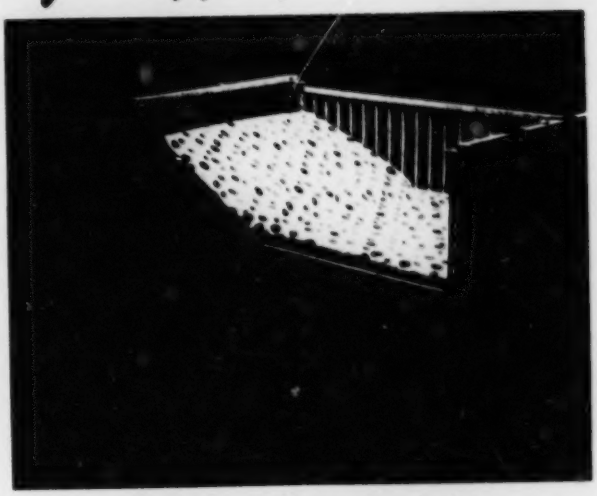

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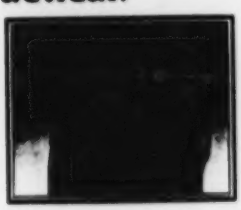

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Circle #2

continued from page 14

severe mental retardation, Jason would have to be heavily sedated during this recovery time.

I hope to find other families who have a child with DMC. I'd also like to hear from parents of children who have undergone spinal fusions, as well as parents of children with other rare forms of dwarfism.

K.R., Michigan

Loss of Skills

My son, Geoffrey, who has cerebral palsy, turned four last March. At that time, he was able to name objects, letters and numbers, and recite simple books, songs and nursery rhymes. He repeated words and phrases on command; and on his own, he repeated words, sentences and phrases he had heard. He communicated his wants verbally—for example, saying, "outside?" when he wanted someone to bring him outside to play. He was learning to stand by holding onto furniture, and he was able to bear his full weight on his legs and feet.

However, over the last six months he has lost all of these skills. Now, his knees buckle when I try to help him stand. He'll go an entire day without speaking more than one or two words. He doesn't want to look at books; he whines or pushes them away. His therapists describe him as becoming "more withdrawn."

I have wracked my brain trying to come up with any change in Geoffrey's life that might help to explain these changes. When he first started this decline, he was diagnosed with fluid in one ear. A few weeks later it was gone, but sometimes it comes back. Around this time he also started to have a sleeping problem that continues to this day—at least once a week, he wakes up around 2:00 a.m., and stays awake until that afternoon's nap. At first, he would wake up and talk all night—reciting books, phrases and rhymes. Later, he started laughing all night. Then,

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Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1995 Resource Guide* (January 1995).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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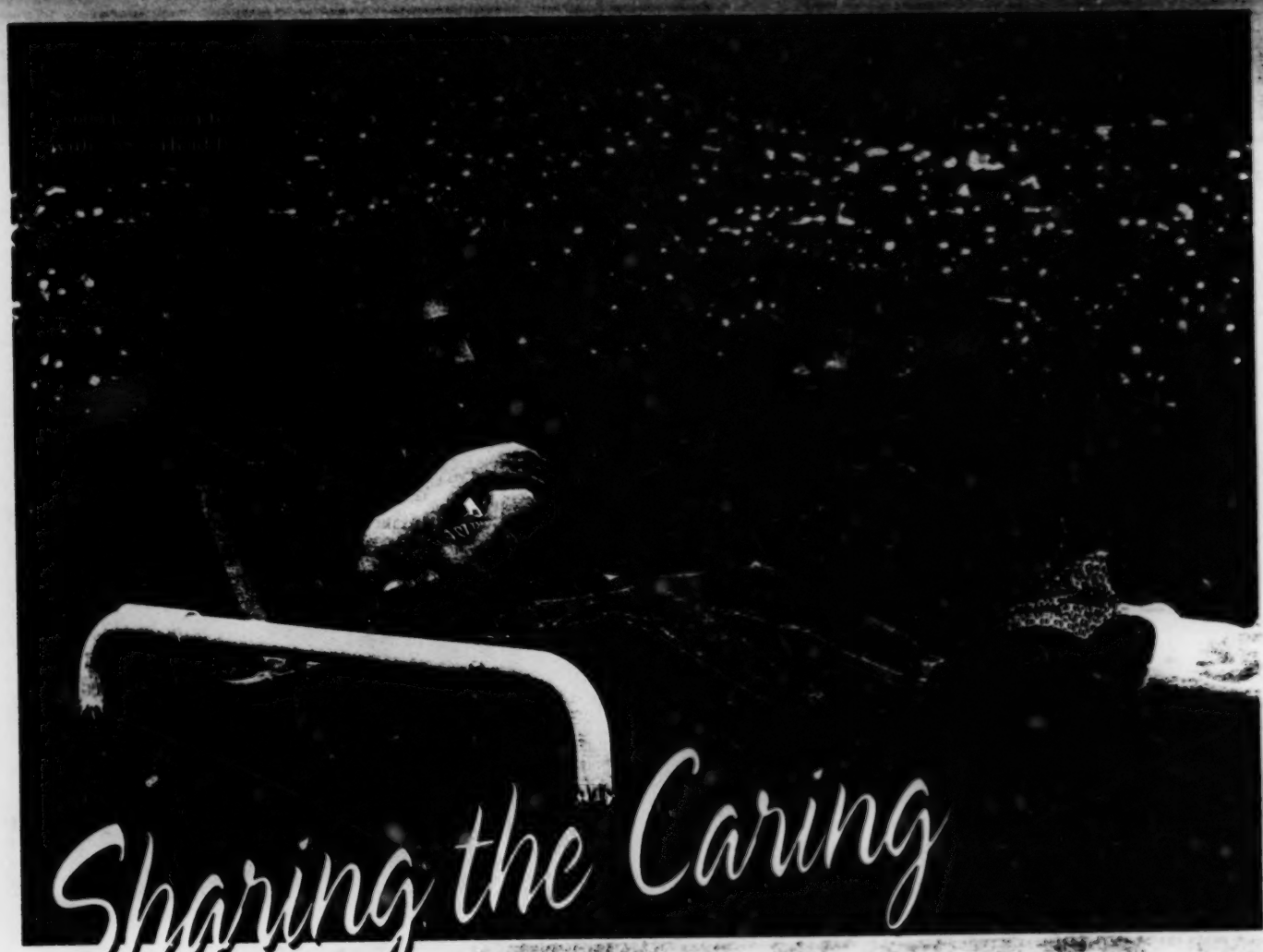

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Circle #88

continued from page 16

when he stopped talking, he began to just babble or make a kind of "E-e-e-e" noise all night.

At first, I worried that the seemingly-obsessive laughter was a type of seizure, but his neurologist says it is not. Now I'm thinking the laughter may come from feeling giddy because he is overtired. His loss of strength and speech may also stem from exhaustion. His vision and ears have been checked; he's also had an MRI and EEG. None of these tests show anything new.

I love Geoffrey and will accept him for who he is. I just want to make sure he can reach his full potential. I'm sad and concerned about his loss of skills, and his therapists and doctors agree that this is unusual. Does anyone have any advice, information or similar experiences to share?

C.E., New York

Episodic Ataxia

My seven-year-old son has moderate developmental delays; he is more like a four- or five-year-old, both mentally and physically.

About two years ago, he developed a new problem. Whenever he plays actively for 10 to 20 minutes, his body just "quits" on him. He starts walking like a drunk, his hands "claw," his arms extend, and his head tilts down. Within minutes, he can barely sit up. He recovers after resting for a half hour or so.

These symptoms have been diagnosed as "episodic ataxia." Doctors prescribed Diamox (acetazolamide), which seemed to help somewhat. Unfortunately, this drug seemed to affect his appetite, and he stopped growing and gaining weight. He is no longer taking it.

Has anyone had experience with episodic ataxia? I want to be able to understand this condition and be sure we have a proper diagnosis.

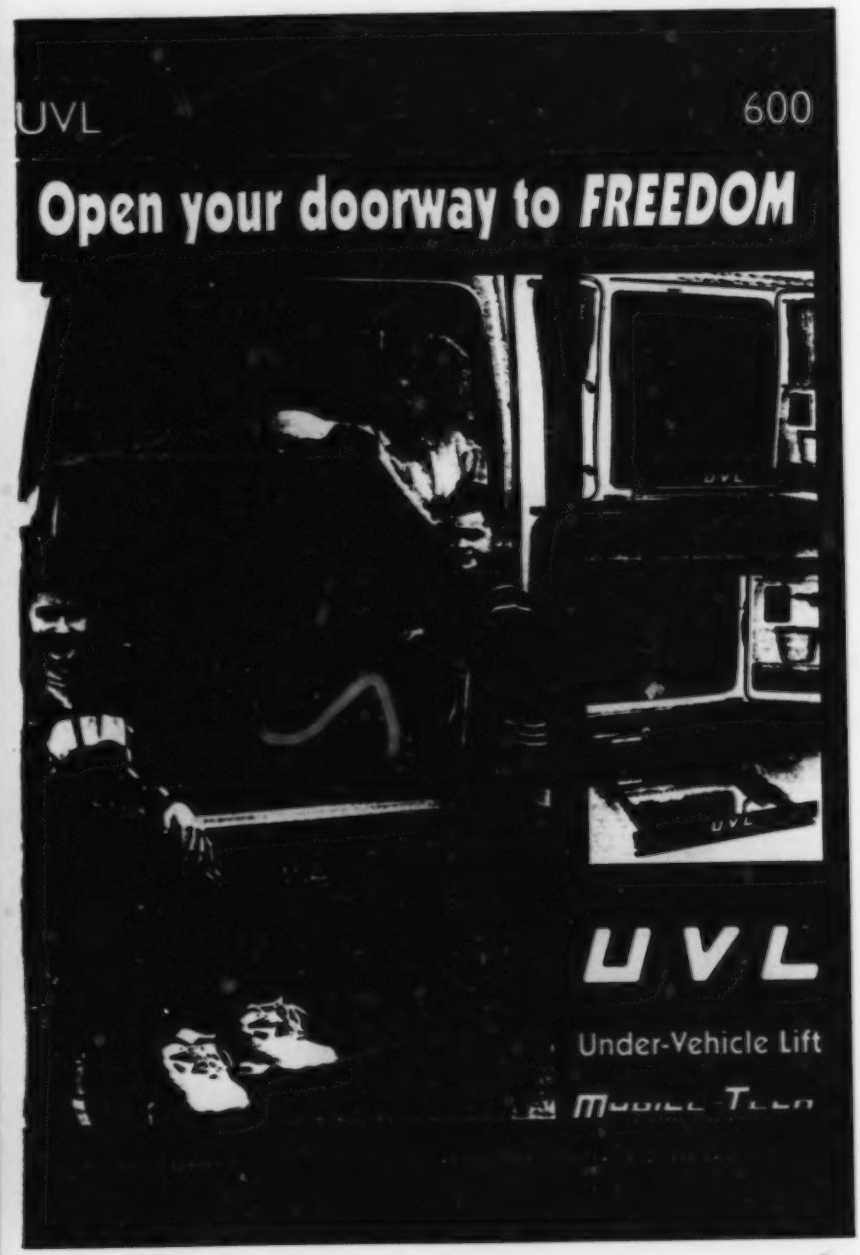
D.G., Florida

Triosephosphate Isomerase Deficiency

Our three-year-old daughter, Ashley, is a very bright child who has been diagnosed with triosephosphate isomerase deficiency (TPI). TPI is a rare enzyme deficiency characterized by chronic hemolytic anemia, hypotonia and neuromuscular breakdowns that occur with viral infections. We would like to hear from anyone, anywhere, who can provide us with support and information about this disorder.

A.S., Louisiana

EDITOR'S NOTE: A British organization, the Research Trust for Metabolic Diseases in Children (Golden Gates Lodge, Weston Rd., Crewe, Cheshire, England CW2 5XN; 01144-1270-250221; 01144-1270-250344, fax) can provide information on TPI; they can also put you in touch with other parents of children with this condition.



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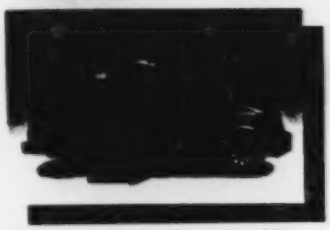

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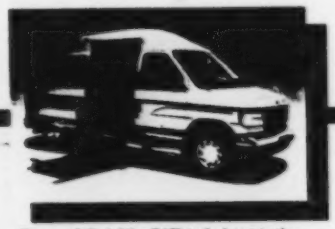

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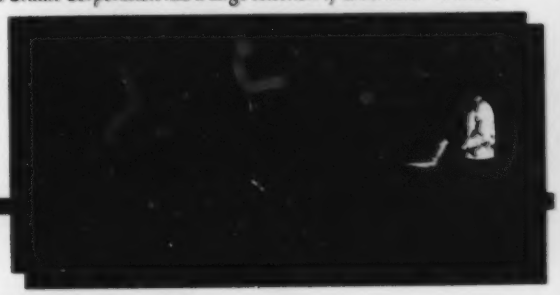

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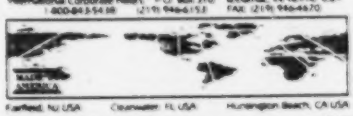

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RESPOND

Leg Braces and Ripped Clothing

M.R. (December 1995) has a six-year-old daughter, Maria, who has spina bifida. Maria constantly rips her clothing when the material gets caught between her braces and the walker. Maria is very fashion-conscious and likes to dress up for school; however, most of her nice clothing now has rips and tears. M.R. was seeking solutions to this problem.

Our daughter, Emmy, 5, also has spina bifida and uses braces and a walker. Like Maria, Emmy would rip her clothing when she walked. We watched what she was doing, and noticed that when she moved her walker, she would bump it with the hip section of her braces. This metal hitting metal—with the fabric in-between—was putting holes in her clothes.

We partially solved the problem by placing a piece of pipe insulating material (found at hardware stores) on the back bar of her walker. We wrapped the insulating material with some strong tape. This has made a big difference, but she still gets small pin holes in her clothes. I try to buy multi-colored clothing so these small holes will not show as quickly. I have also put iron-on denim patches inside her school uniform, at the hips. This, too, has helped.

Finally, we have explained to Emmy that bumping her walker against her braces will ruin her cute clothes. She understands this and has tried to become more responsible in caring for her clothing.

P.K., Kentucky

Biting Problem

C.H. (November 1995) is the mother of 18-month-old Ryan, who has brain stem hypoplasia, myoclonic seizures, mild cerebral palsy and profound mental retardation. Ryan also has a very strong bite reflex and a tendency to put his right hand into his mouth. Although he tries, Ryan can't pull the fingers out of his mouth until the reflex is completed; by that time, his fingers are bleeding. C.H. wanted to find a way to keep Ryan from biting his fingers that would not involve restricting his arm movement.

Our son, Joshua, had a similar problem. About the only thing he could do for himself was to put the tips of three fingers in his mouth. This was not a problem until he got teeth. Then he pressed his fingers against his upper and lower teeth until his fingers were macerated.

I took the problem to our excellent pediatric dentist. He was very supportive and showed me an article about this

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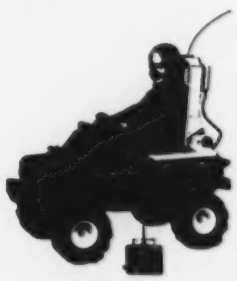

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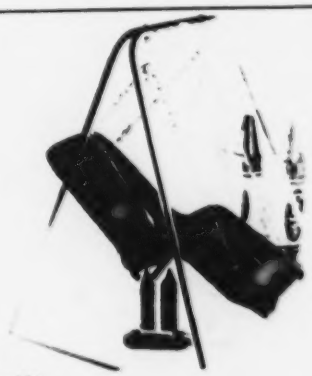

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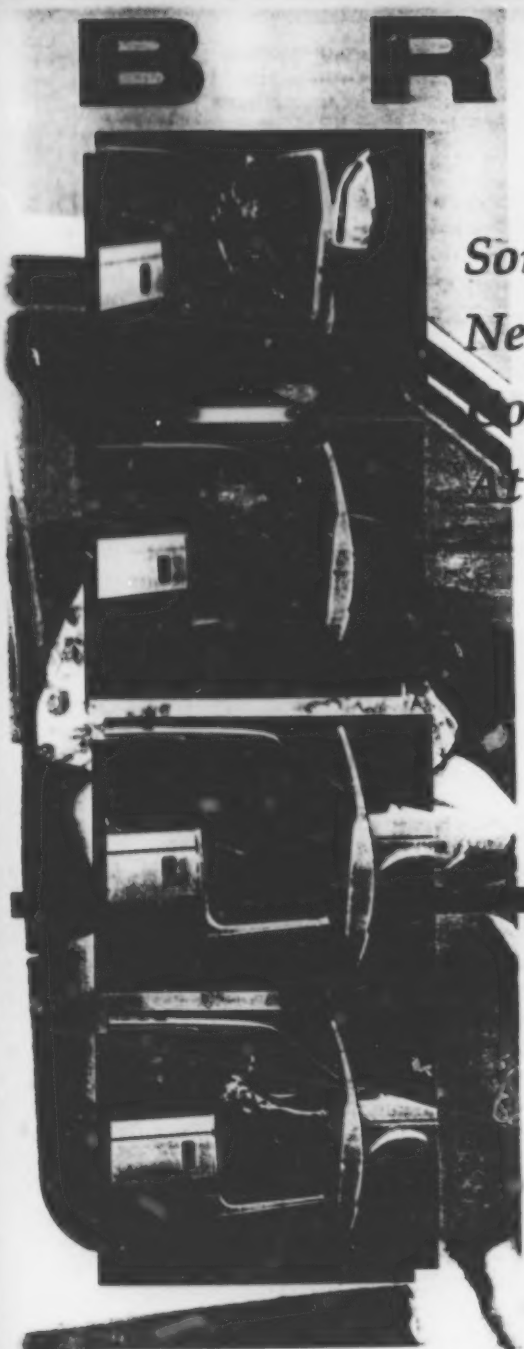

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If you need financial assistance, Chrysler offers cash rebates towards the purchase of adaptive equipment through the Chrysler Corporation Automobility Program. Ask your local Braun distributor about other sources of assistance.

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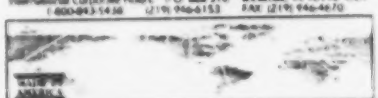

Fairfield, NJ USA Clearwater, FL USA Huntington Beach, CA USA

The Braun Corporation is the international leader in mobility products. With four divisions and a worldwide distributor network, we are positioned to provide the equipment and services you need. Our commitment to your satisfaction is also supported by our Three-Year Worry-Free Limited Warranty. Simply call 1-800-THE LIFT for the Braun dealer nearest you.

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Circle #77

continued from page 22

problem in a pediatric dental journal. I was surprised to learn that this situation is not uncommon in children with very severe disabilities.

The dentist suggested removing Joshua's four upper and lower front teeth. It seemed like a radical solution—and a baby's first teeth are so special—but given the damage Joshua was doing to his fingers, I agreed. This solution allowed Joshua to enjoy the comfort of his fingers, but without the pain. He was tube-fed, so he really didn't need the teeth anyway, and his missing front teeth didn't detract from his special beauty.

Joshua's time with us was short, but memories of his sweet spirit will always remain with our family.

N.F., Utah

Side Effects of Anticonvulsants?

B.D. (December 1995) has a four-year-old son, Christopher, who was diagnosed with a low grade astrocytoma brain tumor at eight months. At 18 months, Christopher was walking and learning to speak. When he started to have seizures, his doctors put him on Phenobarbital, then added Tegretol. As the dosages of both medications were increased, Christopher began to stumble when he walked. He is now unable to walk, talk or comprehend language; he has also started to drool. B.D. suspects the drugs are to blame, but doctors tell her that Christopher's deterioration is not a side effect. B.D. was looking for others who have had similar experiences.

Our 16-year-old son, who has cerebral palsy and a seizure disorder, has taken both Phenobarbital and Tegretol, though never at the same time. It has been our experience that both drugs negatively affect mobility and concentration. Some negative effects of anticonvulsants may be unavoidable, however, your son's condition sounds serious enough to investigate the possibility of changing the dosage of the drugs or the drugs themselves.

Our son was on Phenobarbital for his first six years. During this time he had about five to six grand mal seizures per day. He also had many periods of glassy-eyed staring (petit mal seizures), each of which lasted several minutes. There was noticeable improvement in seizure control when a combination of Tegretol and Tranxene was substituted for the Phenobarbital. However, he had other problems with that combination; he became much less alert and less able to focus his eyes.

Several times during our child's seven years on Tegretol, the dosage was too high. This caused serious problems with coordination and concentration. His coordination, always poor due to his cerebral palsy, worsened to practically no control. He normally is quick to answer us with a smile, facial expression or sound. (And these days, he also uses augmentative communication.) He is bright and has a wonderful sense of humor. But when the Tegretol dosage was too high, he sometimes went several days giving us no response at all.

Dosage is a difficult problem with both Phenobarbital and Tegretol because the optimal blood level varies from one individual to another and because the "acceptable" blood-level range is broad. We have had problems convincing some doctors that the dosage was too high or just that "something is wrong," because they seemed to view their job as simply controlling seizures rather than optimizing quality of life. If the seizures were under control but our son could not function, some doctors had the attitude of, "Well, he's handicapped; what do you expect?" He's had four different neurologists in 16 years because of this attitude. Our son feels that some seizures are more acceptable than the side effects of higher drug dosages that might control the seizures entirely.

Three years ago, our son began using Neurontin (gabapentin). At that time, the drug had been available only for about a year; many doctors are still unfamiliar with it. During his first few months on this drug, our son's coordination and energy level improved dramatically. He also lost most of the little muscular spasms we had always attributed to movement quirks caused by his cerebral palsy; now we think they may have been mini-seizures.

If your son's doctors will not work with you, change doctors and/or get second and third opinions. You should also try to uncover as much information as possible about the potential side effects of these drugs. Start with your pharmacist, who can often be persuaded to part with a copy of the technical flier that comes with each drug. Libraries, bookstores and the Internet are other excellent sources of information. Also, while you are in the neurologist's waiting room, get friendly with the other people waiting there. Some of them will have had experience with the same drugs your son takes, and some of them will have changed to or from something else for some reason. Most people dealing with health problems are happy to share their hard-earned experience.

Remember that doctors are supposed to provide health services. If your doctor is providing seizure control at the expense of your son's health, he is not providing adequate services and you can "fire" him. It may be worth driving a long distance to a new doctor if you get better results and don't have to make as many appointments. Don't give up! Keep talking to people. You never know where you might get a good lead toward solving your problems.

M.B. & A.C., Washington

Diagnosis Found

D.C. (October 1995) was seeking a diagnosis for her three-year-old son, David, who has hypotonia (low muscle tone), scoliosis (curvature of the spine), cataracts and nystagamus (rapid, involuntary eye movements). Several responses to D.C.'s *Search* appeared in the February 1996 issue.

Recently, D.C. wrote to let us know that David has been diagnosed with a mitochondrial disorder known as **oxidative phosphorylation.** D.C. would like to hear from parents of other children with this diagnosis.

Correction:

On page 48 of the February 1995 issue, photos of two strollers—Convaid's Cruiser Ready and Kid-Kart's Kid-T-Rex—were inadvertently juxtaposed and, therefore, misidentified. EXCEPTIONAL PARENT regrets the error.

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Familiar Faces

Fifteen-month-old "biker" **Mackenzie Bockwoldt** doesn't have her license yet, but decked out in her Harley Davidson tee-shirt and perched on Daddy's bike, she looks more than ready for the annual motorcycle rally in Sturgis, South Dakota. When not out on the road, Mackenzie, who has Down syndrome, lives with her parents, Denise and Mark, in Clearwater, Florida.

Soaked to the skin but still smiling, 12-year-old **Quentin Hays-Miller** (center), his mother, **Kathy Miller** (right), and his friend, **James Halemeyer** (left), had a blast on the Thunder River ride at Six Flags amusement park. Quentin, now 14, has cerebral palsy and lives in Frankford, Missouri. He loves watching baseball and basketball on television.

Ten-year-old **Timothy Louder** spends every Saturday morning in "cooking class" with his grandmother, Edith Rose. "He has been preparing food for three years and just loves it," writes Edith. This particular Saturday found the future chef demonstrating the proper technique for rolling out pastry dough. Tim, who has Williams syndrome, lives with his parents, Judy and Dan, in Watervliet, Michigan.

Two-year-old **Kara Lynn Walls** (left) and her big brother **Kirby,** 4, are not just siblings; they're best buddies. Kara Lynn and Kirby, who live in Wall, New Jersey, spend their winters sledding and their summers playing in the water. Kara Lynn, described by her mom, Melinda, as a "happy, affectionate, little sprite," has hypotonic cerebral palsy and microcephaly.

With a little help from Grandpa **Ken Orr,** four-year-old **Rachela Maria DeAngelis** investigates a new mobility option—the wheelbarrow! Rachela, who has partial trisomy 2p/partial monosomy 2q, lives in Dearborn, Michigan, but loves spending time at her grandparents' cabin in the northern part of the state. "Rachela is beautiful and loving and touches the heart of every person she meets," writes Rachela's mother, Sue.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

Let's Go to the Mall!

by Michael and Debbie Nicholson

"Let's go to the mall. Grab Missy's stroller, okay, Debbie?"

"I would, but we broke it on our last trip downtown. I'll carry her for a while, then we can take turns until we buy another stroller."

"Actually, isn't she getting a little big for a stroller? And as far as carrying her, I'm not getting any younger or stronger… and she's not getting any lighter."

"All right, let's stay home then."

Fortunately, things change. During a routine office visit, Dr. Richard M. Pauli, Missy's doctor, recommended that we forget the stroller and look into other mobility options for Missy. First of all, he pointed out, someone else always needs to push a stroller. This could foster dependence on Missy's part, he explained, and it clearly sends the wrong message to others about her abilities and autonomy.

After doing some research, we decided we needed a motorized scooter that could be custom-built to match Missy's unique physique. Missy, now 9, has achondroplasia, hypertonia, hyperreflexia and considerable muscle weakness on the right side of her body. Because of the achondroplasia, her legs and arms are significantly shortened. She can walk short distances, but her leg strength and balance typically fail after 50 steps—then she "crashes." A motorized scooter would give her both safety and independence.

Since Melissa got her Bruno scooter, the Nickolson family feels more able to tackle trips in the community. Enjoying the Bristol Renaissance Faire are (clockwise from left) Chris, 10, Mike, Debbie and Melissa, 8.

The Bruno pediatric scooter fit the bill. Bruno technicians measured Missy's arms and legs, so they could create a customized scooter. After making sure it fit and going through "driver training" at the Bruno plant, Missy was ready to tackle everyday tasks like trips around the community or just playing outside in the neighborhood.

Missy turned out to be a natural driver. When her school bus pulls up in the morning, she drives onto the ramp, waits for liftoff, then drives into the bus.

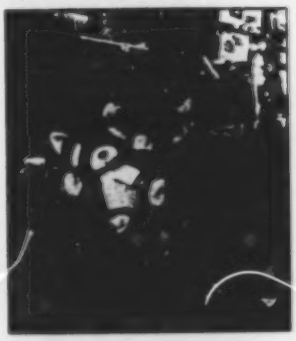
The school district will soon provide Missy with a laptop computer and printer; then the scooter will be modified to carry this equipment from class to class. We have Dr. Pauli's advice and Bruno's craftsmanship to thank for Missy's newfound independence.

"Let's go to the mall, Missy. Pull your scooter behind the van so we can use the Bruno scooter lift, and we'll be on our way in five minutes."

Eight Reasons I Like My Bruno Scooter

by Melissa Nicholson

1. It makes me the same height as all my classmates.
2. I can get places faster.
3. It is very comfortable.
4. It carries my books to school. In fact, everyone uses the basket on my scooter. It's like bringing a shopping cart everywhere you go.
5. I can go shopping with it in the malls where I could not go before.
6. I can go for walks in the neighborhood with my mom.
7. I can ride it all by myself.
8. And it goes up hills.



"Having a scooter is like bringing a shopping cart everywhere you go," says Melissa. The basket is especially handy when Melissa hits the mall.

The Bruno Scooter: A Practical Solution

When considering powered mobility, many parents and professionals think only of power wheelchairs. But as Melissa's story so vividly illustrates, motorized scooters can be an appropriate means of powered mobility for many children and young adults. In fact, a motorized scooter can be a more practical and less costly mobility option.

Bruno Independent Living Aids of Oconomowoc, Wisconsin has been manufacturing scooters since 1990. Bruno has been a leader in integrating modern techniques for seating and positioning into its scooter design. "Proportional Sizing" means many key scooter components can be adjusted for individuals differing in stature, ability to balance, strength and dexterity. These adjustments provide comfort, proper posture, ease of driving and safety. All scooters run on batteries, and some can be disassembled for transporting.

Melissa's scooter, the Regal Pediatric, is on a larger platform than the Cub Pediatric pictured in the advertisement on the next page. Melissa uses a 12-inch-wide youth seat and a power seat lift so she can modify seat height for different activities. Seats are available in a variety of fabrics, vinyls, sizes and shapes, and with different types of padding to provide support without risking pressure sores. Even individualized seating systems can be attached to Bruno scooters. Since Bruno manufactures its own seats and most other scooter components, the company can modify components to meet unique needs.

Melissa's backrest was constructed using extra foam, which moves her forward to provide better posture and access to the tiller. Armrest pads were adjusted to the forward position. The handle to adjust the tilt of the tiller was modified to extend closer to Melissa, allowing her to reach it more easily. The tiller also includes the throttle, which controls speed. The steering tiller and throttle can be adjusted to be controlled by fingers, thumb only, one hand or two hands. An optional "Supervised Speed Control" was included with Melissa's scooter; this allows her parents or teachers to limit scooter speed when appropriate.

When individuals do not live within driving distance of the factory, the Bruno team relies on the recommendations of therapists and dealers to create specially-designed scooters like Melissa's. In other locations, larger dealerships may have scooters available for test drives; special arrangements can be made to ship a scooter for a trial.

For more information about scooters, contact Bruno Independent Living Aids, 1780 Executive Dr., P.O. Box 84, Oconomowoc, Wisconsin 53066; (800) 882-8183 or (414) 567-4990; (414) 567-4341 (fax); or check out the Bruno Web site at http://www.bruno.com/ on the Internet.

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A+ Exceptional Children Deserve An Exceptional Scooter

Children are exceptional and deserve exceptional opportunities. To go and to do. To explore the world around them.

The new Cub™ Pediatric gives your child the freedom to plan his or her own personal voyages of discovery.

The Cub is easy for a child to use, with a compact width that permits exceptionally tight turns. And the Cub is available in front or rear drive.

Each Cub Pediatric includes an Adaptable Seat, for exceptional comfort. Seating and positioning are critical for a growing child.

Proportional Sizing™ is also standard, because no two children are the same and no two diagnoses are identical. Bruno believes your child is entitled to an exceptional fit and support.

And the Cub offers a rainbow of exceptional color choices: bubblegum pink, emerald green, electric blue, cranberry red and viper yellow.

Please call 1-800-882-8183, or 1-414-567-4990 for a free product video and Cub brochure.

We can also be reached at our fax, 1-414-567-4341, or at http://www.bruno.com/

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AD 2000

Circle #240

So... Why Was *Your* Baby Born Early??

by Teresa Wolding

Is it just me? Or, do other parents also sense a growing intolerance directed at the families of children with disabilities—from lawmakers in Washington to people in our local communities? Have you, like me, wondered why? Well, I think I may have discovered part of the answer.

At a recent conference on prenatal care and women's health issues, I saw table after table stacked high with educational literature aimed at teaching pregnant women to "prevent birth defects" through healthy habits. Of course, prenatal care *is* important; however, health educators and health care providers continue to miss—or ignore—the big picture.

Erin Wolding, born at 25 weeks gestation weighing one pound, eight ounces, spent her first five months in the neonatal intensive care unit (NICU) of the hospital where she was born. She survived with cognitive disabilities, a visual impairment, a seizure disorder and severe cerebral palsy. Her twin sister, Jessica, born eight days later, spent three months in the NICU. Jessica has mild cerebral palsy.

Campaigns of blame

I resent public education efforts that perpetuate the myth that prematurity or low birthweight is caused primarily by pregnant women who smoke, drink or use drugs. A March of Dimes public service advertisement I saw a few years ago in a popular parenting magazine is a good example. The ad depicts the footprints of two newborn infants—in the center of the page, the footprint of a very tiny, obviously very preterm infant is dwarfed by the large, plump, "healthy" footprint beside it. The caption reads simply, "Guess which baby's mother drank while she was pregnant."

Guess which baby's mother drank while she was pregnant.

If you're pregnant, see a doctor now.
Fight low birthweight.
March of Dimes
Campaign For Healthier Babies

This ad and others like it represent sensationalism at its worst. Has anyone at the March of Dimes stopped to consider the impact of these campaigns of blame? Families of very premature infants often face the sorrow of neonatal death or, at the very least, great uncertainty about the future of an infant who has somehow managed to survive. But added to this private anguish, these families must deal with the fallout from these "public awareness" campaigns.

Do the creators of these ads realize that they foster finger-pointing and condemnation aimed directly at mothers? I believe the negative implications of these ads have affected all levels of our society. More and more, mothers of children with disabilities are being made to feel that we somehow "deserve what we got" because we created our children's conditions through our irresponsible choices.

"Mom, did you do drugs?"

As the mother of two prematurely-born children with disabilities, I resent health care professionals and members of the general public who would conveniently lump me into the category of mothers who injected, ingested or inhaled the wrong thing during pregnancy. But worse, I worry about the impact of these ads on my children and others.

Several years ago, my then-six-year-old daughter, Jessica, and I were riding in the car when we heard a public service announcement on the radio about drug use and its potential effects on a fetus. The ad warned pregnant women to remain drug-free in order to prevent births of infants with disabilities. My daughter, who has mild cerebral palsy, was silent for a few moments, then turned to me with wide eyes and asked, "Mom, did you take drugs while you were pregnant with Erin and me?"

A similar situation involved the

children of a good friend. Her youngest child was born prematurely but survived with many complications. Her older son was confronted by a child at school who taunted, "I know why your sister is a stupid retard—your mother did drugs when she was pregnant."

In fact, prematurity is a very complex medical issue, and many risk factors for premature delivery have nothing to do with substance abuse. For example, nearly half of all twins—like my daughters—and more than two-thirds of triplets are born prematurely. Women whose *mothers* were given DES hormone (diesthylstilbestrol, a non-steroidal synthetic estrogen, once prescribed to prevent miscarriages) while pregnant with them, often have cervical and/or uterine abnormalities that make it difficult or impossible to carry a baby to term. Pregnant women with diabetes mellitus or toxemia are at risk of preterm deliveries. Very young women as well as women older than 35 are also at increased risk. Both placenta previa (a condition in which the placenta attaches too low in the uterus) and placenta abruption (a condition in which the placenta separates from the uterine wall) can result in preterm delivery and other complications for both mother and baby.

Christmas 1992: Twins Erin (left) and Jessica, 6, enjoy a holiday hug.

But perhaps more startling is the fact that many preterm deliveries happen to healthy, caring women for reasons that will never be known. They simply happen… and it's nobody's fault.

A false sense of security

It is time for all caring parents to say *enough already!* If our society is going to make legitimate progress toward the prevention of premature births, *all* women need to learn the truth about prematurity and its potential complications. The overly simplistic messages of these "public awareness" campaigns give pregnant women a false sense of security—a belief that preterm birth simply won't happen to someone who eats healthy foods and avoids tobacco, alcohol and illicit drugs.

Before the twenty-first week of gestation, every pregnant woman—especially those who are at high risk for preterm delivery—should be taught the easy technique of self-monitoring for subtle preterm contractions. This small intervention may go a long way toward preventing premature deliveries because preterm labor can often be halted with medication, as long as it is caught early—before it has advanced to the point of no return. I've talked with hundreds of mothers who have delivered babies prematurely; the overwhelming majority never even realized they were actually in labor until it was too late.

We can continue to pour money into "public awareness" efforts of questionable usefulness, but until prenatal education improves, and the people responsible for these public awareness campaigns acknowledge the bigger picture, prematurity is destined to remain the number one cause of newborn death and disability. **EP**

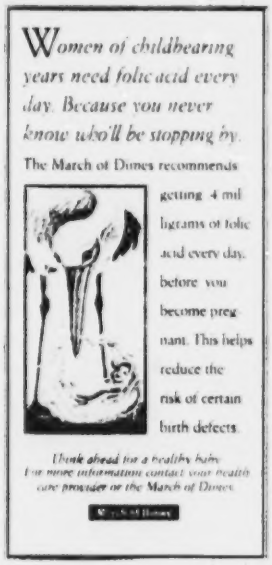
Teresa Wolding lives in rural central Wisconsin with her nine-year-old twin daughters, Erin and Jessica. Teresa, a part-time student, is an active advocate for neonatal ethics and services for families of children who survived premature births. Both Erin and Jessica attend a local elementary school. Erin receives specialized education for children with severe disabilities, including part-time integration into a regular classroom. Jessica, a fourth-grader, enjoys reading, riding her horse, Skippy, and playing with her cat, Gizmo. This article first appeared in the newsletter of the MUMS National Parent-to-Parent Network (c/o Julie Gordon, 150 Custer Ct., Green Bay, WI 54301-1243).

Statement From the March of Dimes

The March of Dimes ad mentioned in Ms. Wolding's article was developed a decade ago and is no longer in active use. It was based on studies that linked growth and developmental delays to maternal alcohol use.

While our educational campaigns change over the years, the one thing that remains constant is their basis in science. There is a great deal we do not know about preventing birth defects and preterm birth, and the March of Dimes has long supported research to better understand their causes. When we do have scientific data about maternal behaviors that can increase the chances of a healthy birth, we have an obligation to pass this information on to the public and will continue to do so.

We would be happy to hear from EXCEPTIONAL PARENT readers on this subject. Your comments can help guide our future public service advertising and educational campaigns. Contact the March of Dimes Birth Defects Foundation, 1275 Mamaroneck Ave., White Plains, NY 10605; (914) 428-7100; (914) 997-4662 (fax).


Women of childbearing years need folic acid every day. Because you never know who'll be stopping by.
The March of Dimes recommends getting 4 milligrams of folic acid every day, before you become pregnant. This helps reduce the risk of certain birth defects.
Think ahead for a healthy baby.
For more information contact your health care provider or the March of Dimes.

The newest March of Dimes public service announcement is part of the organization's "Think Ahead" campaign, which encourages women of childbearing age to consume at least 0.4 milligrams of folic acid every day in order to reduce the chances of giving birth to a child with a neural tube defect, such as spina bifida.

Geri Jewell, 39, is an actress, comedian, public speaker and writer, who is probably best-known for her role as "Cousin Geri" on THE FACTS OF LIFE, *a television sitcom of the early 1980s. Jewell continues to perform stand-up comedy, but has also embraced a key role in the community—consulting to Fortune 500 companies on compliance with the Americans with Disabilities Act (ADA). Jewell says, "I'm trying to increase awareness and the potential of hiring people with disabilities, valuing people of all walks of life and realizing that we need to take advantage of all our assets."*

Jewell lives in Las Vegas, Nevada with her husband, Richard, and two stepchildren, Ben, 18, and Holly, 27. The following was adapted from an interview between Jewell and EXCEPTIONAL PARENT *intern Amanda Young.*

Geri Jewell

Learning "The Facts of Life"

I was born prematurely. It was a very traumatic birth; my mom was hemorrhaging, so they were trying to save her life. They thought they had lost me because they couldn't find a heartbeat. But somehow, I was still in there. I weighed three pounds when I was born, then I began losing weight. The doctors didn't think I was going to live. Finally, they figured out that bananas were the only thing that would put weight on me and keep me alive. I ate bananas for the first three months of my life, then they released me from the hospital. And now, I hate bananas.

"My parents had a natural tendency to overprotect me," says Geri, shown here at age two with her parents and brothers, Fred and David, "but I tried to keep up with my two older brothers and my sister, Gloria, who was born three years after me. I had to do everything Gloria was doing—riding a bike or whatever. My parents couldn't hold back one kid and not the other."

From the time I came home, my parents knew intuitively that there was something wrong with me. But, doctors would say, "She's only 16 months old. What do you expect her to be doing?" Out of frustration, my mom called around and found out that, at that time, the leading hospital in detecting birth defects was UCLA Medical Center. So, we moved from Buffalo, New York to California. When I was 17 months old, I was diagnosed with cerebral palsy.

An imaginary fence

My education began at 18 months of age, in a private school for children with cerebral palsy, where I remained through first grade. After that, I attended a special-education program in the public schools. I felt very separated and isolated. The special education school was on the same block as the regular elementary school, but we had different playgrounds. It felt like an imaginary fence—I could watch all the other kids playing tether ball over there, but I was not allowed to go beyond a certain point. I didn't pass through the "imaginary fence" until sixth grade, when I got to take regular math and English classes. But every afternoon, I would go back to special ed.

When I was about 14 years old, I had a special education teacher who made a real difference in my life, who gave me an opportunity to shine. I was in a class of 13 students, all whom were performing below grade level. This teacher took one look at us and told our parents, "These kids are supposed to enter high school in a year, and none of them have any idea what they have coming to them." So she came up with a plan to prepare us.

She started by asking each of us one question: "What do you want to do when you grow up?" Nobody had ever asked me that before. I almost drew a blank, but after thinking for a few moments, I told her I wanted to be an actress, a writer and a comedian. So my assignment for that year was to write three plays and produce one. I had to cast it, direct it and build the set. All the students in the school and all our parents came to see it. I had such an overwhelming sense of accomplishment. As special education students, we were always told, "You can't do this; you can't do that." And after a while, we began to believe it. But this teacher gave each one of us a starting point, and this was mine.

High school

High school was a very difficult time. I had always been in special classes, so I was very immature and had few social skills. On my first day of high school, I showed up wearing saddle shoes, a jumper and knee socks, and carrying a Davy Jones lunch box. I can't tell you how embarrassing it was to realize I was the only kid on campus who was dressed like a ten year old.

In 1981, during her first appearance on *The Facts of Life*, Geri (center) clowns around with series regulars (from left) Lisa Whelchel, Kim Fields, Mindy Cohn and Nancy McKeon.

During my high school years, I retreated into my own world. When I got my license, I started driving to the library four or five nights a week. My mother was thrilled I was taking my schoolwork so seriously. She didn't know I was at the library reading every book on show business. I pretended the library was MGM, and that I was a star going to work.

I was not only below my age level socially and emotionally, but I also lacked academic skills. There were only certain classes into which I was allowed to be mainstreamed, but, somehow, I got put into a ninth grade English class. One of our first assignments was to write a book report. In all my years of education, nobody had ever asked me to read a book, much less write a book report.

A few days after I turned in my book report, the teacher asked to see me after class. She said, "Geri, I don't mean to offend you, but I want to know, I really want to understand... *what on earth makes you believe this is a book report?*"

I told her, "You said it had to be 200 words; and I counted, and it's exactly 200. You said to break it up into paragraphs, so I indented every five lines. I put some commas in... and, look, I even have a semicolon."

The teacher was shocked. She realized I did not know how to write. She could have had me transferred out of her English class and put into a special class. But instead, she took it upon herself to tutor me after school. She not only taught me to write, she convinced me that someone cared about what I had to say.

Learning the facts of life

I graduated from high school in 1975 and went to Cypress College, a junior college. In my junior year, I transferred to Fullerton College, another junior college in California. I vacillated between majoring in psychology or theater arts. But the truth was that I just wasn't academically ready for college, and after three years, it was starting to catch up to me. I drove my instructors crazy because they didn't know what to do with me. They couldn't understand how I could be so intelligent, yet lack so much knowledge and maturity. I felt overwhelmed, and responded by stacking up my hardest classes for my senior year. Looking back, I realize I was setting myself up for failure. But I don't believe there is real failure in any experience if you can learn from it.

I regret that I never graduated from college, but I left school with a determined will to succeed in the entertainment industry, if only because I didn't have to pass anatomy or physiology to do it. Actually, it felt like there was nothing else I was qualified to do. I remember diligently trying to get a job one summer. I tried everything from drug stores to fast food outlets. I even tried to join the Army. It didn't take me long to realize I had no job skills. So, I moved to Los Angeles and started doing stand-up comedy every night. I probably lived in about 20 different places during that first year in LA. I was learning how to survive and how to deal with setbacks. It was my first taste of reality.

I got the role of "Cousin Geri" on *The Facts of Life* by being in the right place at the right time. Norman Lear and

continued on page 42

In 1985, after The Facts of Life had ended, Geri was invited to visit the White House. "At the time," Geri says, "I was one of the most visible persons with a disability in the country, but I was flat broke. I couldn't even pay my rent."

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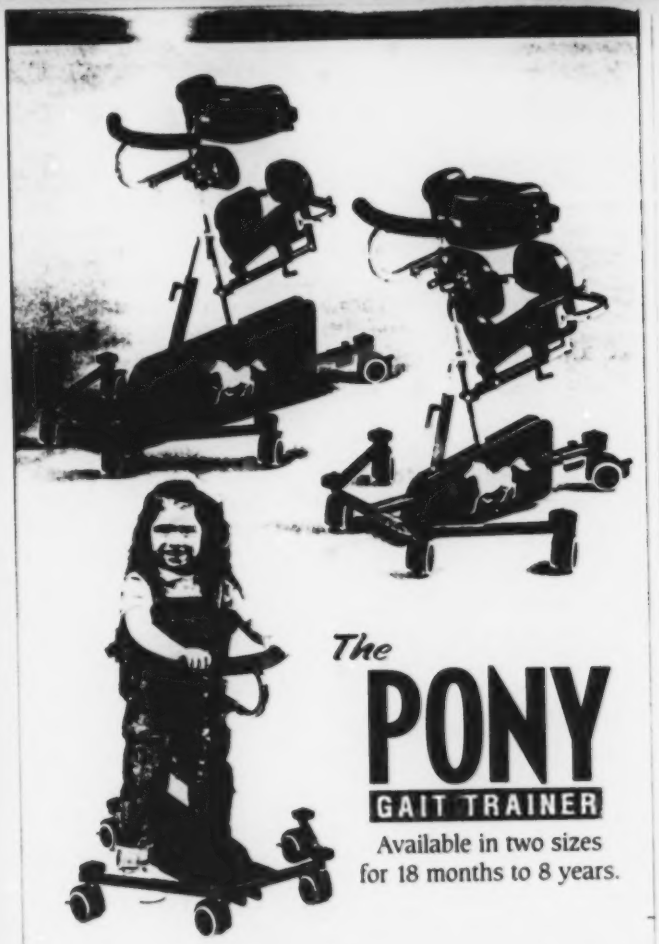

Versatile. The Gazelle is a standing frame, prone board, tilting table and drainage wedge

Drainage position –15

Individual abduction Max. 60

The GAZELLE
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Circle #210

continued from page 31

Al Burton, the show's producers, and some other people connected with the show came to see one of my comedy acts, and one thing led to another. It was 1981, the U.N.-designated "International Year of the Disabled," and the show's writers wrote a script especially for me. My first appearance on the show was well-received, and I was asked back as a semi-regular.

I was 23 years old. Chronologically, I was an adult; but emotionally, I was like a child star. I pretty much assumed *The Facts of Life* would never end. I just thought it was going to last forever.

To the public, I was a kind of superhero, a person with a disability who was very visible on a prime-time series. In my own life, however, I was a scared little girl who believed anything anybody told me. When *The Facts of Life* ended after four years, it taught me some hard lessons about human nature, survival and looking at the world and at myself more honestly.

Flat broke

In 1985, I was invited to visit the White House. The irony is that I was flat broke at the time. It seemed hypocritical to go to the White House representing a successful person with a disability, knowing all the while that when I flew home, I wouldn't be able to pay the rent. But I accepted the invitation and carried it off as honestly as I could. I'm not belittling my accomplishments up until then, but at the time, I didn't feel at all successful.

It was a painful period in my life. I was unemployed and down to zero money. It astounded me that the entertainment industry could embrace me one moment and have no place for me the next. I was angry, bitter and hurt. I almost gave up because I couldn't come up with any vision for my future. Luckily, there were enough people in my life who were honest with me and not willing to feed

Geri describes fellow comedian Flip Wilson as "extremely kind and funny." His advice to her (or any other aspiring comedian)? Write one new joke a day.

Newlyweds Geri Jewell and Richard Pimentel on their wedding day at The Little Church of the West in Las Vegas.

into my self-pity. They told me, "You did it once and you can do it again." They kicked me in the butt.

Picking up the pieces

I started to pick up the pieces around 1986, when I began to do lectures and train companies about people with disabilities in the workplace. I first started getting invitations to give keynote speeches because, you know, I was "Cousin Geri." But it evolved into a skill. I learned about the ADA; I learned about the importance of attitudes. I was good at what I was doing, and it allowed me to find myself again.

In 1990, I wrote a script for and played an undercover cop in an episode of *21 Jump Street*. Although doing the show didn't turn out to be a springboard back into the entertainment industry, that week of work was one of the most rewarding weeks I have ever had, even better than working on *The Facts of Life*. I did *21 Jump Street* as an adult and as an artist, and I went into it with my eyes open—knowing that I might not work again for another three years. I was in it just for the enjoyment of working again.

We can do more!

I'm proud of the work I've done. I feel it has had a positive effect on society. When I was on *The Facts of Life*, I got tons of mail from kids. It broke down the barriers. It's like what Chris Burke did on *Life Goes On*. His work on that show helped kids feel more comfortable with children who have Down syndrome.

Unfortunately, the entertainment industry still does not realize the impact that people with disabilities could have. Why can't one of the characters on *Friends* or *Beverly Hills 90210* have a disability? It doesn't have to be me, but the industry has all these opportunities to create new role models for young people to identify with and doesn't use them. What I did on *The Facts of Life*, what Chris did on *Life Goes On*, when they put a wheelchair user on the Wheaties box—these things made such an impact. But we can do so much more. **EP**

Geri Jewell may be contacted at P.O. Box 36386, Las Vegas, NV 89133.

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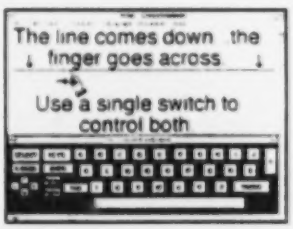

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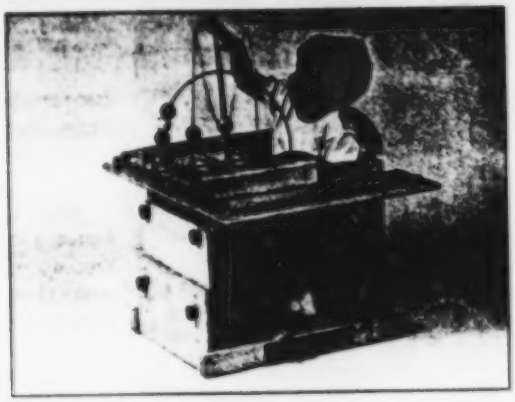

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Circle #196

Healing Broken Dreams

by Robert Naseef

ILLUSTRATIONS BY MICHELLE WHITE

I'll never forget the magical night my son was born. Even before his tiny body had completely emerged from the birth canal, he seemed to look all around the delivery room. Without thinking, I jumped up to stand right beside the doctor—my knees wobbling, my heart pounding.

Right away I could tell that Tariq's head was the same shape as mine. I counted his fingers and toes and watched eagerly as the nurse cleaned him and wrapped him in a blanket. He looked so cute—a perfect newborn. The nurse placed him in my arms, and I felt the electricity of the instant when Tariq's big, round eyes met mine for the first time. He was soft and delicate to my fingertips, and I cradled him next to my heart. It was one of the most exciting moments of my life.

Through my son's development, the wonder of life was revealed to me in a way I could never have imagined. I marveled as he progressed from lifting his head, to rolling over, to crawling and to cruising around holding onto furniture. I can still recall his look of apprehension, replaced by a smile of achievement, as he took his first awkward, wobbly steps on his first birthday. What an amazing accomplishment! That is still one of my most vivid memories—of a time when he was "normal."

As Tariq continued to meet developmental milestones—including the development of a small but useful vocabulary—I began to dream of our future together. I imagined him playing Little League baseball. In my mind's eye, I beamed with pride as he fielded the ball and swiftly ran the bases. I would be the perfect father—there for him when he needed to talk, but able to give him space when he wanted it. I imagined the two of us having philosophical discussions. Our relationship would be close and warm.

In June of 1981, when he was 18 months old, Tariq got sick with a virus. His illness was treated and went away, but my son never got better; he never spoke another word. I was sick with worry as Tariq's engaging personality became a mere memory. He seemed to have no interest in people, but would play with the same rattle for hours on end. When he was diagnosed with autism, I was flooded with the deepest grief of my life.

Dreaming... and waking up

Struggling to accept my son's condition, I began to work with Tariq, using methods suggested by his speech therapist and other techniques I had read about. For example, I would imitate Tariq's repetitive movements—like flapping my arms when he flapped his. When I did this, Tariq would usually notice, give me a little smile, then just go back to what he was doing.

But in a recurring dream, my efforts did not go so unrewarded. In my dream, Tariq would watch intently as I mirrored his behavior. Then, as my heart beat faster with excitement, he would slowly

continued on page 38

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Bob and Tariq enjoy a crisp, cool autumn day beside the water at Marsh Creek State Park near West Chester, Pennsylvania.

continued from page 37

form a word or two. I would hug him, overcome with emotion.

In the first mornings that followed this dream, I awakened full of hope. I saw this dream as a sign that Tariq would speak to me again, if only I would work with him to make it happen. Desperate to document evidence of Tariq's progress, I taped his grunts, groans and babbling. I listened to these tapes for hours on end, straining to hear the emergence of meaningful communication.

Eventually, I began to wake up from this dream feeling exhausted and overwhelmed. Whenever I'd worked hard at something in my life, I had gotten results. But now my hopes for Tariq's recovery were fading. It was hard to fathom that I might have no control over my child's condition, still more difficult to admit that love was not enough to help my son.

Moving forward

Around Tariq's eighth birthday, I had a different dream. In this dream, my son spoke to me in sentences, and I reacted with amazement, relief and joy. But as the dream continued, although still asleep, I became conscious that I was dreaming and that Tariq had not really spoken. The next morning, I awoke with a deep sense of relief. I had a sense that I could live with things the way they were, that I could be a whole person despite Tariq's silence.

That dream recurred over three or four years, and then was replaced by a new one. In this dream, Tariq talked to me again. Looking at me intently with his big brown eyes, he told me that he loved me, felt my love for him and knew I had done everything possible for him. He told me he was happy and that he wanted me to be happy, too. Then he returned to playing with his tongue and making unintelligible noises, seemingly unaware of my presence. In the dream, I felt sorrow and longing for what could have been, if only Tariq could

***Fathers' Voices** is a regular feature of EXCEPTIONAL PARENT magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

have continued talking. But I woke up with a definite sense that I had moved a little further on my journey.

A deeper life

In truth, some of my greatest joys have been in moments Tariq and I have shared. His disability is severe but does not affect his soul, his inner essence. Despite being unable to read, write, talk or relate normally to others, Tariq has been and continues to be a catalyst for a fuller, deeper and more loving life than I ever imagined possible.

Because of Tariq, I have learned to tune into the signals I used to miss. When happy, he shows interest and excitement. When startled, he raises his eyebrows and opens his mouth and eyes wide. I can only use empathy to understand him—but what power lies there! In a world that values reason and intellect above emotion, children like Tariq teach us to look inside ourselves.

Nature gave me a fair amount of intelligence and ability, but before Tariq, I held my frustration and anger inside and could not articulate my emotions to others. Tariq taught the little boy in me to speak. Now I know well the shades and colors of all the emotions in my inner life—both positive and negative.

The other side of sorrow

While writing this account, I retrieved one of those tapes from a dusty box in our basement. Listening to this 12-year-old tape brought back a flood of old emotions. I heard myself patiently trying to coax meaningful sounds out of my young son. Then I couldn't listen any longer, because it hurt too much to realize that Tariq still makes the same vocalizations—only now, with a deeper, post-pubescent voice.

There are millions of children like Tariq—some with more ability, some with less. These "imperfect" children are born to loving parents who struggle to rise from disappointment to find a stronger love, a more perfect love that lies on the other side of sorrow. Life can be so full and rich amidst all the difficulties. I feel good about how far I have come, but the cost has been great—my only wish is that I could have done it another way. **EP**

Bob Naseef lives in the Philadelphia area with his wife, Cindy. In addition to Tariq, their blended family includes three daughters: Antoinette, 14, Kara, 4, and Zoe, 2. Tariq, now 16, resides at the Devereux Kanner Center in nearby West Chester, Pennsylvania. Bob is a psychologist specializing in serving the families of children with disabilities. He enjoys gardening and photography and serves on the board of directors at the Center for Autistic Children in Philadelphia, where Tariq was once a student. He is working on his first book.

Illustrator Michelle White is the mother of three children, including six-year-old Kate, who has Down syndrome. Michelle's artwork was featured on the cover and inside the June 1994 issue of EXCEPTIONAL PARENT. She may be contacted at Hidden Hills Studio, 624 Hilldale Rd., Holtwood, PA 17532.

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Circle #224

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Voice-carryover and hearing-carryover provide an additional benefit to some relay users. For people who have trouble hearing, but no trouble speaking, AT&T offers voice carryover, or VCO. With VCO, the relay service user can place a call through the relay center and speak directly to the person being called, relying on the CA to type only what that person says. With hearing-carryover, a relay service user with a speech disability can listen directly to the other person on the call while the CA voices what the person with a speech disability types.

There are no special charges for making relay calls. The calls are billed in the same way as standard telephone-to-telephone or TTY-to-TTY calls—according to the call's length and destination. Relay customers are eligible for the same long-distance toll discount plans as any other customer.

AT&T became the first telecommunications company to provide a 24-hour-a-day, 365-days-a-year relay service when it began providing relay service in California in January 1987. AT&T now provides long distance relay services for customers all over the United States, as well as local services in several states. Relay service calls can also be placed in the Spanish language through the AT&T Spanish Relay and to English-speaking persons in international locations. If you would like to learn more about the AT&T Relay Service, please call AT&T Relay Customer Service at 1-800-682-8786 (TTY) or 1-800-682-8700 (voice).

Telecommunications relay service is just one of the services that allows AT&T to be more than just a major telecommunications company—it demonstrates that AT&T is a corporation that cares.

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

AT&T Employee Fred Weiner

Looking forward to spending a year "on the Hill"

I joined AT&T Accessible Communication Services because I had a very strong personal and professional interest in deafness. Because of my background, I believed that I had an opportunity to make an impact in a unique way.

Born into a deaf family in 1963, I lived in Brooklyn until attending Gallaudet University in Washington, DC, where I received a degree in accounting. I was a charter member of the Deaf President Now movement, which brought about the selection of the first deaf Gallaudet President in the university's 124-year history. I stayed in the DC area until 1990, when I took a job at AT&T and moved to New Jersey.

I'll be spending this year "on the Hill" as a Congressional Fellow in the office of Rep. Robert Andrews (D-NJ), through the Brookings Institution's Center for Public Policy Education. The Brookings Institution is a private, nonprofit organization devoted to nonpartisan research, education and publication in economics, government, foreign policy and the social sciences. The Brookings Congressional Fellows Program places private industry managers as legislative aides in Congressional offices to foster better understanding between business and government.

I expect this experience to have a definite impact on my career. For one thing, I'll be working on areas other than deafness. I've always had a strong interest in the political process; this fellowship will give me a better understanding of the social and economic implications of legislative issues, and of the ways legislation affects businesses. I'll get to meet new people and establish networks that will prove valuable over time. Finally, it will make me a stronger manager and a more valuable employee for AT&T.

As a hard of hearing person who is part of the deaf culture, I love Washington, DC, and I am enjoying the opportunity to spend some more time in this area. I have always dreamed about working on the Hill for "just one year." That's why I couldn't believe my eyes when I saw the announcement of this opportunity for a one-year assignment. It seemed made to order just for me. Still, I was really surprised when I was chosen, and I'm really excited about it all.

Thinking about the coming year makes me a little nervous, but I do love politics. I love the give-and-take, the issues and the dramatic impact politics has on people. Unfortunately, not too many people participate in the process, despite its strong influence on their daily lives. I'm not here to represent AT&T or our corporate views, but I do know that the people I meet will see me as an AT&T employee, so I am aiming to represent the company in the best way I can.

—Fred Weiner

Fred Weiner is a sales manager with AT&T's Accessible Communications Services division, and was responsible for the start-up and management of the New Jersey Relay Center. When not "on the Hill," Fred lives in Maryland with his wife, Lynn Ballard-Weiner, who now teaches at the Maryland School for the Deaf, where their two daughters, Allison Joy, 4, and Bethany, 2, are students.

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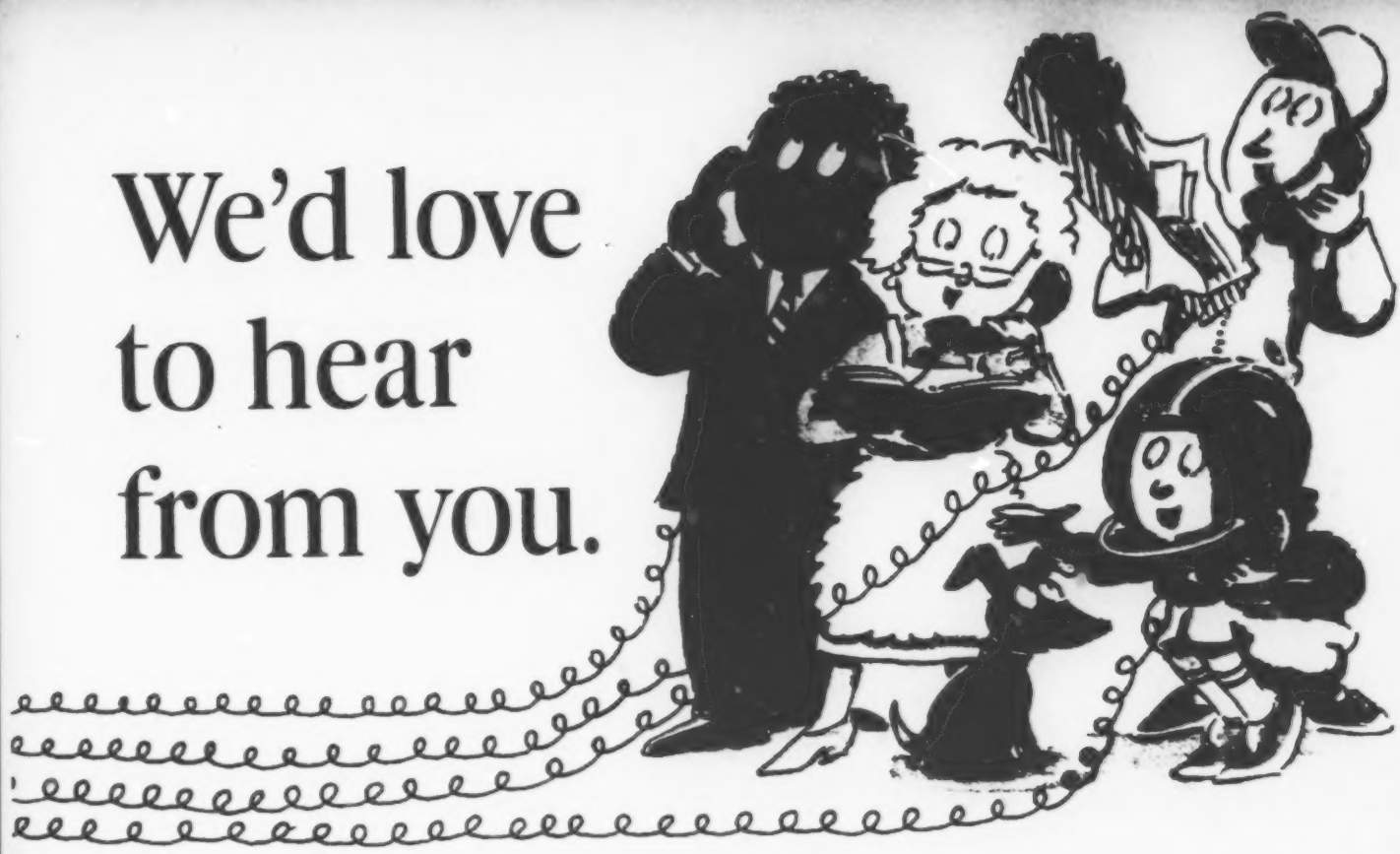

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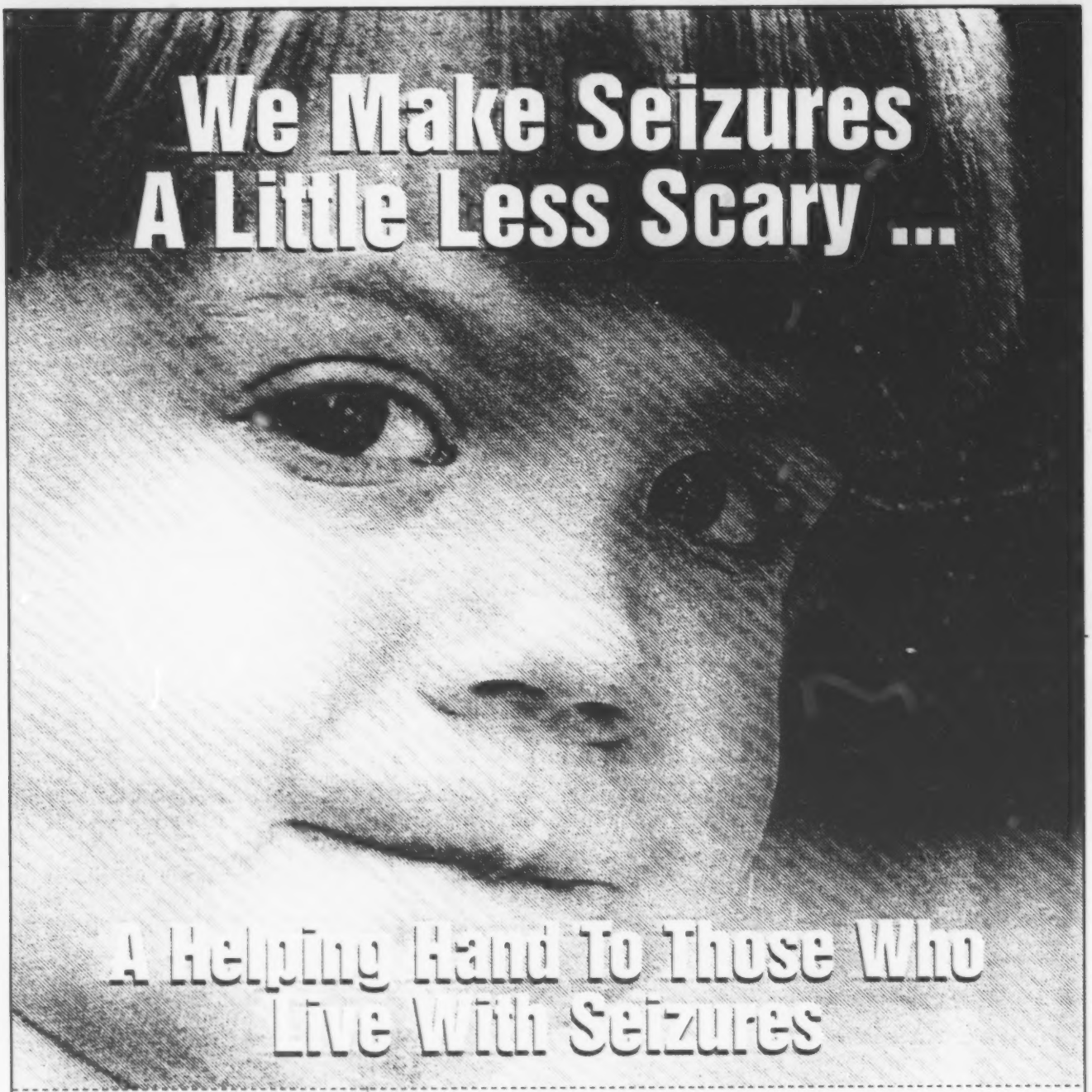

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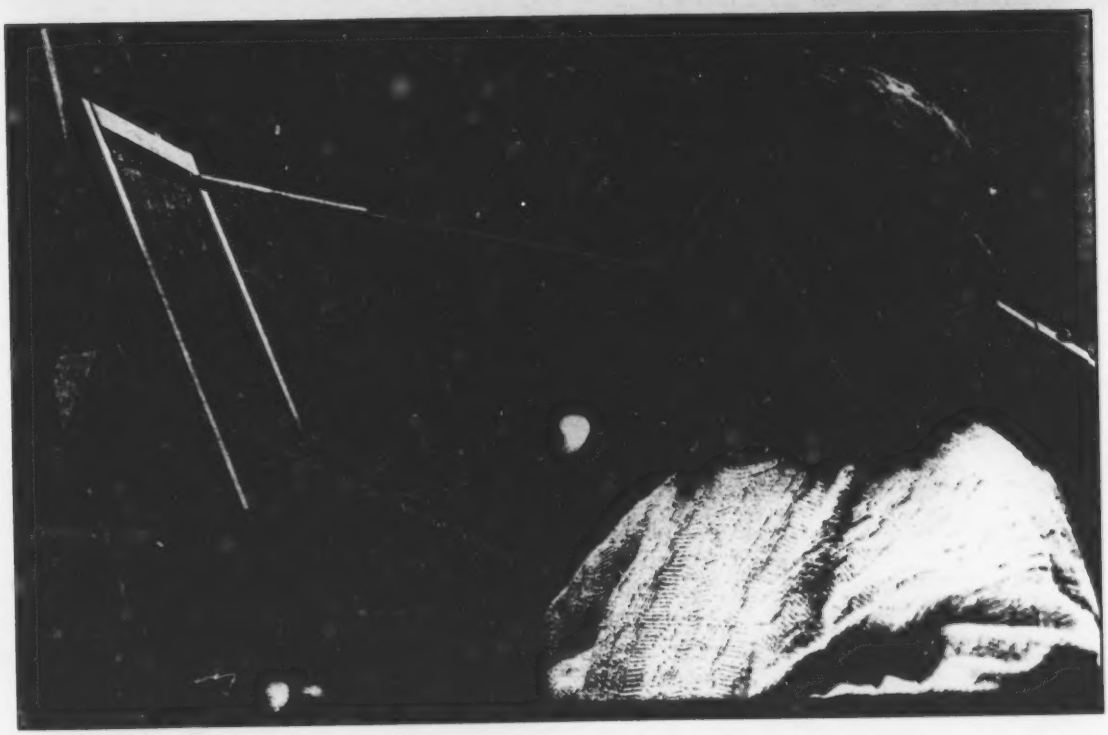

The Joy of Independence

Spring Time by Amy Neubauer

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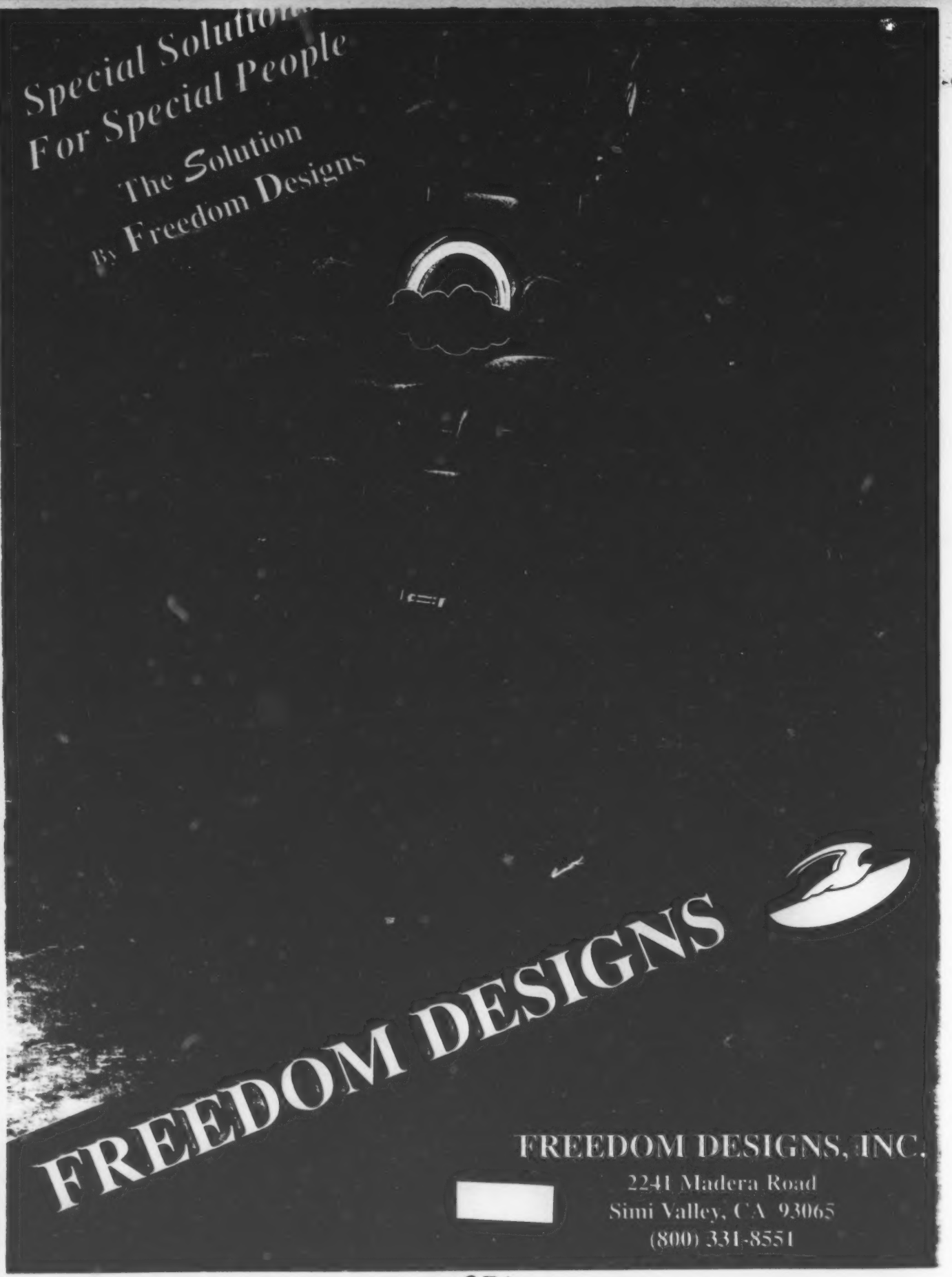
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The "W-word"

by Don and Vicki Nelson

Although it was two and a half years ago, we vividly remember the day Andy's physical therapist first mentioned the "w-word"—wheelchair! Our hearts sank to the bottom of our stomachs, but we had to admit that our son's motor difficulties were becoming more apparent with each passing day. We felt numb as we faced the reality that Andy, who had been born with cerebral palsy, was just not going to be independently ambulatory for long distances.

It really hit us on the day we saw Andy being pulled into his school building in a little wagon. We realized he was at the constant mercy of others. We knew Andy's therapist was right; it was time to explore other mobility options. Because Andy could not maneuver a manual wheelchair independently, it was clear we needed to explore power mobility.

The long, stressful process of getting Andy a power wheelchair began with Andy's pediatrician referring Andy back to his physical therapist for an evaluation. His physical therapist had Andy practice "driving" for a few months, after which she submitted her recommendation for a power chair to our HMO. Unfortunately, the HMO would agree to pay only one-third of the chair's cost. The rehabilitation technology supplier who worked under contract with the HMO helped us submit a financial aid application to Minnesota's medical assistance program (TEFRA). On the last day of our application's six-week review period, we got word it was going to be denied, apparently as a result of TEFRA officials misinterpreting our physical therapist's recommendation.

At the time, there were fears that TEFRA itself might lose its funding. We were afraid that by the time we appealed their denial—and waited through another six-week review—there might be no aid left for Andy to receive, even if our application was approved. So, instead, we got the phone number of our case's TEFRA authorization agent and called to argue our case directly. Shortly thereafter, our application was approved, and Andy finally got his power wheelchair, almost a full year after we began the procurement process.

Andy's power wheelchair has given him a completely different view of the world. His new ability to explore his environment has led to many questions about how and why things work—ideas he might not have thought about without the opportunity for independent exploration. Andy's therapists still believe he has great potential to use his walker independently over short distances, so perhaps it is somewhat fortunate that our home is not wheelchair accessible. Because Andy can't use his wheelchair around the house, we have a chance to continue working on his transitional and ambulatory skills within our home, while the wheelchair allows him greater independence in school and in the community.

Andy's newfound independence has not come without some minor drawbacks, if you can call them that. Although Andy has made wonderful progress in refining his "driving skills,"

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Circle #14

Andy's school day begins with a ride on a lift-equipped yellow school bus.

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he continues to need safety reminders. His new independence has also given him what we like to call "the liberty of defiance." We struggle to strike the proper balance between his dual needs for independence and safety.

The benefits of power mobility—for both Andy and for us—far outweigh our initial fears of the ways the "w-word" might impact our family. We now view power mobility as an alternative our son not only needs, but, more importantly, something he *deserves*. Andy's delight in his independence and his increased self-esteem often bring tears to our eyes. However, these are tears of joy and pride, not the tears of sorrow we once feared.

Out in the community, we still receive our share of furtive glances from the people we see. We used to assume these people were curious about Andy's disability. But now we find ourselves confidently smiling and nodding back at them, wondering if they aren't more impressed with Andy's *ability* to use power mobility than with his *inability* to walk. **EP**

Don, Vicki and Andy Nelson live in Rosemont, Minnesota. Don is a middle school teacher. Vicki, who is pursuing a degree in nursing, serves on several committees addressing concerns of children with disabilities and their families. An earlier version of this article appeared in MEETING GROUND *(Fall 1995), a publication of Courage Center, Minneapolis, Minnesota.*

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Circle #292

Sharing Information

A roundtable discussion of mobility issues

Recently, a panel of experts gathered to talk with Exceptional Parent *about mobility concerns; one area of specific interest to all participants was the flow of information among parties involved in making mobility decisions—doctors, therapists, parents, technology retailers, third-party payers and children themselves. The panel included: Jean Minkel (JM), M.A., P.T., a member of the RESNA-ANSI Committee on Wheelchair Standards and president of Minkel Consulting in New Windsor, New York, a firm offering guidance in the provision of assistive technology; Carrie Larson (CL), O.T.R., a pediatric occupational therapist with a private practice based in Bedford, Massachusetts; Adrienne Bergen (AB), P.T., a rehabilitation technology supplier with Dynamic Medical Equipment in Westbury, New York and a member of* Exceptional Parent*'s Editorial Advisory Board; and Ruth-Ann Rasbold (RR), an inclusion specialist at the Federation for Children with Special Needs in Boston, Massachusetts, and the parent of Megan Rasbold-Gabbard, a 13-year-old middle school student who uses a wheelchair.*

Adrienne Bergen, P.T., rehabilitation technology supplier:

"I would like to see everyone feel more comfortable in identifying needs. That a need exists doesn't mean there is a failure... A need is just a need; it should have no value judgment attached."

Getting started

AB: The process typically begins when someone identifies a problem that needs a solution. Something isn't happening—it's either something the child can't do or something the parent can't do easily. If a parent is having difficulty transporting or transferring a child or young adult, the parent can identify that as a problem that might be solved with technology. Parents shouldn't feel they just have to deal with the situation the best they can.

Nor should therapists be afraid to look for solutions. Many therapists, especially therapists working in early intervention, have little information about different types of equipment, or they see the use of technology as a failure in the therapy process.

I would like to see everyone feel more comfortable in identifying needs. That a need exists doesn't mean there is a failure, or that someone is a complainer, or that someone is not strong enough—emotionally or physically—to deal with something. A need is just a need; it should have no value judgment attached.

JM: I think it is helpful to ask parents, "What would you like to do that you can't do now?"

The answer might be something like, "I can't go to the store; everybody takes their kids to the store, and I can't even get out to go grocery shopping."

Then you move on to, "Well, let's think of some ways that we can make that happen. What devices or techniques can we use?"

RR: When Megan was about two, her physical therapist showed us a travel chair in a catalog and told us, "I think that this is what Megan needs."

And I said, "Absolutely not!" First of all, the chair was *ugly*. And second, I knew a few other families who had purchased these chairs and found them not useful and too heavy. The chairs ended up sitting in basements or garages.

But the therapist didn't want to listen to my reasons. She just said, "Well, if you're not ready to deal with that, we don't have to talk about it now."

CL: See, that's what we were talking about—it becomes judgmental. That therapist was judging the mom and saying, "She's still in mourning. Isn't that sad?"

Instead, she should have been asking, "What do you need? Do you need something to help you move Megan around? Should we look into something that can help Megan move herself around?"

All or nothing

AB: Adjusting to the idea that your child might need some kind of mobility device can be a major hurdle for families. Parents

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might ask, "Why is my kid going to physical therapy and working on standing if you're talking about him being in a wheelchair"? When the child is a little older, the issue might become a manual wheelchair versus power mobility— you have a 15-year-old who is going to high school, so maybe he should have a power chair or a motorized scooter. Does that mean he shouldn't walk anymore? Or that he will never walk?

Many clinicians also view mobility as a series of all-or-nothing decisions. Walking versus not walking is the most glaring example. But this can also be applied to decisions like whether or not to use a trunk support.

Let's say the child can sit a little bit, with no external support. And if the child had the external support, maybe he or she could also use a computer keyboard. But the therapist is thinking, "Well, if I put the trunk support there, the child won't work on trunk control anymore."

They see it as all-or-nothing, as opposed to, "Well, maybe the child should use this other chair without the trunk support most of the time, but when the child is doing an activity like keyboarding, maybe we need to give her a little more support."

Unfortunately, therapists learn that technology is something you use if treatment doesn't work.

JM: I agree with Adrienne. If "mobility"—in the largest sense of the word—is truly the goal, I should look at technology as an adjunct to the therapy I'm providing. But Adrienne is right; that is not what we are taught in school.

CL: Fifteen years ago, a study asked if children would stop trying to walk when power mobility was introduced. The findings showed that children who were given power mobility became much more interested in moving themselves around, and that their physical capabilities continued to grow and change.

Ruth-Ann Rasbold, parent:
(shown with daughter Megan, 12, and son Max, 9)

"You could buy a dress for a 12- or 13-year-old girl without asking her if she likes it, but it will hardly ever work out. And the same thing goes for a wheelchair."

Sharing information

AB: I've spoken with many parents who feel they don't have enough information. I always wonder why. Are they given the information when they're just not ready to hear it, so they don't digest it or remember it? Or are clinicians and suppliers holding back, because they are afraid that given too much information, the consumer will make a bad choice?

JM: I think it is important to remember that information-sharing can be a very costly activity. These days, clinicians are under pressure to see more people and to do things quickly. Providing *some* information inevitably leads to more questions, and answering those questions takes time.

CL: I believe that, ultimately, parents end up having to take the responsibility for making sure they have talked with all the various people who could possibly give them input. Information-sharing doesn't automatically happen. Parents need to facilitate the process, whether it's through a set of questions they ask of all team members—including themselves—or through some other means.

RR: At the time we were starting to look into mobility options, Megan went to school with other kids who also needed some kind of alternative mobility besides their feet. So I was always comparing notes with other parents.

And since Megan has gotten her power wheelchair, I'm always getting calls from parents asking, "How does it work? I've heard of you through..." You know, they'll say something like, "Mary's best friend's

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Independence

by Megan Rasbold-Gabbard

I wander hopefully,
Now anxious for an amazing adventure,
Deciding for myself,
Everything is so good,
Promise that I will be happy,
Everybody that is important, friends and family;
Not being lonely, but
Daring to do things alone,
Empowered to be a self-advocate,
Natural leader,
Confident in choosing,
Ecstatic that my wheelchair gives me independence.

Megan Rasbold-Gabbard, 13, is a middle school student living in Lexington, Massachusetts.

Reprinted from Exceptional Parent Magazine, March 1996.

Jean Minkel, P.T.:

"In my training as a physical therapist, I was trained to present myself as the expert. I had to 'untrain' myself in order to be responsive to parents."

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cousin's brother-in-law gave me your number. Can I ask you some questions?" Other families are the best source of information.

Dealing with costs

AB: I think the issue of who is paying boils just under the surface a lot. It can influence the information clinicians provide to families.

JM: Very often, when dealing with third-party payers, therapists won't offer a choice of different types of equipment because they think they can't "justify" certain expenditures.

AB: But information needs to be shared without judgment. Whether or not you can afford a piece of equipment should not determine whether or not you know about it. Parents should have the information either way. A professional shouldn't withhold information.

JM: The managed care companies are definitely coming up with lower-cost options. And if those options work for you, great. For example, you know you want a bath chair. You've used a certain type of bath chair for years and just want it replaced. The HMO can get it at a 50 percent discount and drop-ship it to your house. That's terrific!

But you don't want them to do that with your child's first power chair. You wouldn't have a clue how to get the batteries set up and charged. You would want to have somebody there with you when the chair is delivered—someone to explain how it works, what to do if it breaks, what kind of maintenance it needs.

Still, managed care is giving us an opportunity to reevaluate the way things have always been done. And that is not always a bad thing.

RR: We once had an HMO refuse to buy one of Megan's chairs—not because it cost a lot, although it did, but because this particular chair didn't come with a warranty. The HMO suggested a different chair, which actually cost more money, but which they thought was a better deal. That's the sort of thing managed care should do: look at the bottom line—but in terms of value, not just in terms of cost.

Who is the expert?

AB: Looking for devices that might make their lives easier can be intimidating for parents. They end up surrounded by a lot of experts, and nobody's asking what the parents want. Parents who have identified a need, and who are looking for resources, may want to bring another parent along—maybe somebody who has already been through the process of purchasing equipment. There's strength in numbers.

Many times, unfortunately, therapists get their egos all wrapped up in this. When the family "dares" to ask a question, it sets the therapists back to "I'm the therapist; you're the parent. I'll tell you what's right; I'll let you know when your child is ready for that."

As a supplier, a lot of times families come to me for advice and the first thing I say is, "Please, bring your therapist with you."

And I'll get the reply, "No, I'm not even telling the therapist I'm coming."

JM: I can tell you that in my training as a physical therapist, I was trained to

Low-interest Loans Help Families Purchase Mobility Equipment

In North Carolina, the Program for Accessible Living (PAL) provides low-interest loans to families and individuals who need mobility equipment or other adaptive devices to improve the quality of their lives. The program, run in cooperation with NationsBank, is open to any resident of the state, and can provide loans of $500 to $15,000. PAL reviews the initial application for assistance, and forwards its approval, along with a written quote for the specific equipment, to NationsBank, who processes the loan. Since PAL guarantees each loan (through a pool of grant money), NationsBank gives borrowers the best available consumer interest rate and allows them to extend the terms of the loan a full year longer than usual. In just over two years, the program has granted almost 60 low-interest loans to families and individuals who otherwise might have been unable to afford necessary equipment.

Similar programs exist in Maine and New Hampshire. Nevada, Connecticut and several other states have begun to look to these programs as models for financial aid projects of their own. To find out if a similar program exists in your state, contact your state's assistive technology program (see "State Assistive Technology Programs," January 1996).

—Mike Cisneros

Reprinted from EXCEPTIONAL PARENT Magazine, March 1996

present myself as the expert. I had to "untrain" myself in order to be responsive to parents.

RR: We went from this one therapist implying that we were "in denial" because we didn't want to use this ugly travel chair, to the same therapist telling us we were unrealistic because we wanted power mobility for Megan. In the end, the therapist we worked with had a different attitude—she said, "Why not? Let's assume it can be done until we prove otherwise."

JM: As a parent, you should articulate what you want. Say, "I live with this kid everyday. Now, let *me* tell *you* what I need!"

AB: While a dialogue is going on between a supplier and a therapist, if a parent has a gut feeling about the equipment, like, "It's *ugly*..."

CL: ...or, "I don't have a van to transport it..."

AB: ...or, "Just by looking at this, I can tell it won't fit in my nineteen-inch-wide bathroom," they should just say it. A parent should never feel, "Oh, my God, if I say something, all these people are going to think I don't really want to take care of my kid."

Asking the right questions

CL: Parents know more about their child's capabilities and ambitions than therapists; parents also know what kind of support network they have available. Look to the professional to help you, but not to deliver a definitive answer without your input.

RR: It's also essential to involve the child. You could buy a dress for a 12- or 13-year-old girl without asking her if she likes it, but it will hardly ever work out. And the same thing goes for a wheelchair.

JM: For example, we had a really young child who picked a purple-and-green color combination. Every adult in the room gagged, but when it was delivered, his sister saw it and said, "Ohhh, that is *so* cool!" That kind of reaction really bolsters the self-esteem of the kid who is going to be sitting in the chair.

Another time, I was working with a child who was in middle school, like Ruth-Ann's daughter. The most important thing to this child was that the controls in the back of the chair were covered so the other kids in school wouldn't touch them.

We have to show kids what different types of chairs look like—let them sit in it, but then take them out and show them what the back looks like and what the sides look like. We have to ask, "How this is going to work?" and, "Can your book bag fit here?" and, "Do you have a place for your locker key?"

The make-or-break decision between two models can be something like, "I really need a hook right here; that's what works for me." And those are absolutely unpredictable things.

AB: I like to say to parents: "Think about a whole day in your life. What things are difficult for you? What things are easy? What do you wish you could do that you can't do now?" These questions give everyone a place to start. **EP**

Carrie Larson, O.T.:

"Parents know more about their child's capabilities and ambitions than therapists; parents also know what kind of support network they have available. Look to the professional to help you, but not to deliver a definitive answer without your input."

Advice From Manufacturers of Wheelchairs and Scooters

QUESTIONS TO ASK

- How long will this product be useful for my child? Can it be adapted to accommodate a growing child?
- How long will this product last?
- What are the details of the warranty? How do we get service? How quickly can we get service? Are replacement parts available?
- How can the chair or scooter be transported in the family vehicle?
- How can we travel with this chair or scooter by air, train or bus?
- Are there any problems associated with outdoor use of this product? How does it perform in bad weather?

THIRD-PARTY PAYMENT

In preparing medical-necessity information (for insurance reimbursement) for an expensive product that is expected to last for at least several years, manufacturers suggest estimating the cost per year for the product. Breaking the cost down this way seems to make an approval more likely.

One particular problem has been the tendency for managed care plans to disallow "options" that may be critical to the consumer's unique needs. To deal with this issue, some manufacturers are building models with fewer options and employing new design methods using less expensive materials or less costly workmanship. Others are creating models that come with all the options that previously had to be ordered separately. Of course, these models often include some options that might be unnecessary for some users.

EXCEPTIONAL PARENT thanks the following manufacturers for their contributions to this sidebar: Bruno Independent Living Aids, Freedom Designs, Kuschall of America, Mullholland Positioning Systems, Permobil and Vector Mobility.

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Good News About Wheelchairs and Transportation

by Ned Einstein

To a wheelchair user, mobility is the key to an enriching life. The wheelchair itself is good for going around the block. But to travel longer distances, wheelchair users need access to a car, van, bus or train—just like everybody else. The problem comes when riding in a wheelchair *in* a vehicle: for the past few decades, wheelchair manufacturers have been making chairs lighter and lighter, without regard for the consequences of this approach on the "crashworthiness" of wheelchairs during transportation.

Wake-up call for the industry

Three years ago, in an effort to standardize wheelchair securement devices and their attachment points in school buses, leading school bus transportation providers invited wheelchair manufacturers to a national conference on pupil transportation. The response of the manufacturers was startling—they seemed to have no idea that their chairs were being tied down in school buses and other public transportation vehicles!

After consulting attorneys, many manufacturers began to worry about their liability in the case of motor vehicle accidents. For about a year, every wheelchair sold came with a disclaimer posted on the side. In large letters, it read, "DO NOT USE FOR TRANSPORTATION PURPOSES." Some manufacturers went so far as to send disclaimers to every customer who had purchased a chair in the last 10 years.

Problems that never materialized

While manufacturers panicked about liability concerns, all 50 states required school bus services to provide transportation for wheelchair users. And the Americans with Disabilities Act (ADA) made the same requirement of public transit services. The clash of these mandates with the now-prominently-displayed wheelchair disclaimers raised a number of concerns for families:

- What should I do if my school bus service refuses to transport my child?
- If the bus has an accident, is my child likely to be severely injured?
- If my child is injured, does the disclaimer on his wheelchair prevent us from recovering damages in a lawsuit?

The good news is that none of these problems ever materialized. According to Michael Wagner, co-chairman of a national committee currently developing wheelchair standards, there has not been a single instance of a wheelchair user being refused school bus or public transportation because his or her chair was deemed unsafe for travel. Furthermore, the law in most states does not permit "disclaimers" issued by manufacturers of safety equipment to shield them from liability; nor can the specified use of such products be narrowed to exclude the "normal activities" of the owners. And perhaps most reassuring, early test results demonstrate that most existing wheelchairs are well-constructed, and are quite safe in accidents, as long as they are properly secured.

A more promising future

School bus operators and the wheelchair manufacturing industry—with virtually no government funds (Illinois and Pennsylvania each contributed $10,000 to the effort)—have designed and launched a full-scale safety testing program. The program, started in March 1995 and slated to run for three years, is being conducted in conjunction with the American National Standards Institute (ANSI) and Rehabilitative Engineering Society of North America (RESNA). Financial and analytical assistance for this lofty endeavor—expected to cost in excess of $300,000—is being provided by RESNA's 52-member Subcommittee on Wheelchairs and Transportation (SOWHAT), whose members include experts from universities, state and federal agencies, wheelchair design and engineering firms, hospitals and rehabilitation centers, advocacy groups, school transportation contractors, transportation lobbying organizations and industry associations, and wheelchair manufacturers.

The project will include dynamic crash testing, to be conducted by the University of Michigan, in which both "modules" (platforms containing several rows of seats, intended to simulate sections of a bus) and entire vehicles outfitted with various combinations of wheelchairs and life-like test dummies will be crashed into barriers at various speeds. Testers will film the results and electronically measure crash forces. The results will help wheelchair manufacturers improve the crashworthiness of their designs.

These tests will examine many characteristics of wheelchairs and tie-down systems including:

- securement technologies (such as hooks and straps), their optimal attachment points and their strength;
- specifications and ideal location for wheelchair seat belts and shoulder strap attachments;
- optimum seat back angles;
- optimum wheelchair size and turning radius (the key factors in maneuverability);

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- ideal wheelchair weight and mass;
- properties of materials used in wheelchairs;
- crashworthiness and injury minimization;
- optimal labeling and identification of wheelchair and tie-down components, including directions for proper use;
- for power wheelchairs, battery leakage and sloshing (which compounds risk of leakage and may also make the wheelchair less stable while in transit);
- the effects of any proposed changes on wheelchair comfort.

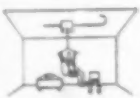
Benefits for wheelchair users

This ambitious effort has two extremely important goals—improved safety and crashworthiness, and the standardization of certain wheelchair characteristics. The project's results—once circulated among wheelchair designers and manufacturers—will provide several benefits to wheelchair users who ride school buses or use other forms of public transportation:

- Wheelchairs will be stronger, more stable and more comfortable.
- In the case of an accident, chairs will hold up better, thus minimizing the risk of serious injury to users.
- Securement devices will be located in easier-to-reach places in transport vehicles, benefiting both users and drivers.
- Increased standardization of securement points and technologies will permit school buses, vans and other transportation vehicles to carry wheelchairs of virtually every type and size.

Funding for this study is being used primarily for such things as the purchase and design of testing equipment and activities. The bulk of the work is being performed by dozens of experts, all of whom are volunteering their time. The study is neither mandated by law nor financed with government funds. Rather, it is being paid for with good will, expertise, generosity, open-mindedness and, most of all, hard work—hard work that is creating a better, more mobile world for all wheelchair users. **EP**

Ned Einstein is the president of Transportation Alternatives, a southern California-based consulting firm specializing in the design of school transportation systems for children with special needs, and "paratransit" systems for adults with physical and developmental disabilities. A former consultant to the U.S. Department of Transportation, Mr. Einstein authored the summary report of the NATIONAL SURVEY OF THE TRANSPORTATION OF THE HANDICAPPED, *a report to Congress that formed the basis of the transportation sections of the ADA. Mr. Einstein conducts workshops on special transportation services and regularly provides expert testimony and technical assistance to attorneys involved in transportation-related cases, particularly those involving paratransit, school bus and special education services.*



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HEALTH

Children with Special Health Care Needs and Managed Care

Important lessons from the Arizona experience

by David Hirsch, M.D. and Thomas Barela, M.D.

Managed care is not a bad concept. It aims to spend health care dollars efficiently, on proven therapies with an emphasis on preventative health care. It seeks to standardize medical care and reduce variation in treatment. These are not bad goals. Unfortunately, it is difficult to standardize the care of children with special health care needs.

There is no question that some form of managed care will soon be applied to most federal- and state-funded health care programs, including Medicare, Medicaid and Title XIX, which are federal entitlements (guaranteed programs that can only be abolished by an act of Congress). Medicare covers much of the health care costs for most senior citizens in the United States, while Medicaid covers health care for some people who could not otherwise afford insurance and for children and adults with disabilities. Title XIX specifically covers individuals with disabilities who have long-term-care needs. For the most part, these federal programs can be considered insurance plans, just like the kinds of plans private employers might offer. But because they are administered and partially funded by state governments, these plans are likely to vary to a certain extent from state to state.

Facing the challenge

Can the fast-changing world of managed care encompass the needs of children with special health-care needs or chronic illnesses? The partners in our private pediatric practice in Phoenix, Arizona first faced that question in 1987, when managed care became a reality for those Arizonans covered by Medicaid or Title XIX.

Our practice, started in 1974, was like most private pediatric practices initially—most of our patients were generally-healthy, typically-developing children. Like most pediatricians, we had a few patients with disabilities or special health care needs, but they received most of their care from specialists.

As time went on, however, we were offered the opportunity to care for the medical needs of children and adolescents living in group homes and, later, skilled nursing facilities. Soon we began getting referrals from local hospitals and state case managers who had young clients with special health care needs. Word of mouth from parents led to still more referrals. As our expertise and reputation grew, so did the number of children in our practice with special health care needs. By 1987, we were caring for approximately 1,000 children with chronic illnesses and special health care needs (not counting children with mild to moderate asthma)—almost 10 percent of our total practice.

In order to continue caring for these children, most of whom were covered by Medicaid or Title XIX, we elected to take the then-novel approach of becoming primary care physicians in a managed care plan for these patients—"novel" because no other private practice had previously been willing to assume care for this high-risk and high-cost population under managed care. In addition, since Arizona was the first state to convert Medicaid and Title XIX to a managed care system, we had little to go on but our own previous experience with a "fee-for-service" system in which payment was based on medical services rendered.

Under the new Arizona plan, known as the Arizona Health Care Cost-Containment System (AHCCCS), coverage would be administered through HMOs, who would bid for these contracts. Once contracts were awarded—based on, among other things, cost and the ability to deliver services in an appropriate geographic area, actual health care services would be provided by physicians under contract with specific HMOs. Often these HMOs would pay contracted physicians a monthly fee (known as the "capitation rate") for each enrolled patient. "Capitation" contrasts

About this article:

"Managed care" can be defined as "the use of a planned and systematic approach to providing health care, with the goal of providing quality care at a lower cost." Managed care is exemplified most prominently by health maintenance organizations (HMOs), and is most commonly characterized by the use of primary care physicians (PCPs) as coordinators or "gatekeepers" of patient care. This means that all medical care other than office visits with the PCP—including referrals, diagnostic studies, hospitalizations and therapies—must be deemed "necessary" and be pre-approved (or "pre-authorized") by the patient's PCP (and sometimes by the patient's HMO as well).

The "gatekeeper" may be the most visible symbol of the main premise of managed care—fiscal restraint in an effort to control costs. Because children with special health care needs typically incur high medical costs, they may be more affected by the restricted benefits more commonly seen with managed care.

Can the fast-changing world of managed care fulfill the health care needs of children with disabilities or chronic illnesses? Because managed care systems vary almost as widely as the needs of individual children, it is impossible to answer this question in any definitive way. But as some form of managed care becomes a reality for increasing numbers of American families, it is clearly time to discuss its potential benefits and risks and present some models for making managed care work for everyone—including individuals with special health care needs. This article, which provides a look at the way one group of doctors and parents in Arizona are finding ways to make managed care meet their needs, will be the first of several to explore these issues.

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A Light at the End of the Tunnel

Years ago, our family joined FHP Healthcare, an HMO available through my husband's employer, the City of Mesa, Arizona. Along with 100 percent hospitalization coverage, we only had to pay $5 for doctor visits and $3 for prescriptions. Although FHP dictated which hospital and specialists we could use, all were well-known and respected. When our son, AJ, was diagnosed with spina bifida during my pregnancy with him, we assumed FHP would cover any costs associated with his care. After all, they didn't give us any hassle about covering frequent ultrasounds and the planned cesarean section.

Unfortunately, AJ was born with a Chiari malformation, one of the most severe complications of spina bifida, in which the brain stem is pulled down into the spinal column. As a result, AJ also has apnea (periodic pauses in breathing), bradycardia (slow heartbeat), aspiration (difficulty swallowing correctly), paralyzed vocal cords and hyperinsulinism (production of excessive insulin, the hormone that regulates blood sugar levels). AJ breathes through a tube inserted into his trachea and is fed through a tube that goes through his nose to his stomach. We brought him home from the hospital along with 30 days of supplies and a great deal of medical equipment.

Once home, we discovered that although our insurance covered all the durable medical equipment, including AJ's oxygen, suction machine and ventilator, they covered no disposable items—such as feeding bags, suction catheters, gloves and gauze. We began to shop around to find the lowest price for each supply. Prices varied greatly; for example, a feeding bag ranged from $2 to $25—and AJ needed one feeding bag a day. Even if we could find the lowest price for each disposable item, we realized our minimum expenses for these items would run $2,000 per month. In a panic, we sold our boat and second car, and planned for financial ruin.

FHP paid for a nurse to check on us once a week, but they did not cover overnight nursing, so one of us always had to be awake. AJ couldn't cough, gag or swallow, so his breathing tube needed frequent suctioning to prevent him from drowning in his own secretions. I watched AJ all day and all night. After work, my husband watched him to give me a few hours of sleep. After 13 days, AJ landed back in the hospital with pneumonia and a virus. We were emotionally and physically exhausted, but we loved our son and each other. We fought off suggestions that we give AJ up or get divorced, just so he could qualify for aid.

With the help of a walker, AJ Moore, 2, proudly makes his way around the house.

Although we had once applied for, and been denied, coverage under Arizona Long Term Care, a social worker encouraged us to apply again. After months of paperwork, we saw a light at the end of the tunnel—AJ now qualified. The City of Mesa met with FHP and agreed to share the cost of a nurse for five nights a week until we were eligible to receive state benefits. Now, anything that is not covered by FHP is covered by Arizona Long-Term Care. We receive all the supplies AJ needs and a night nurse seven nights a week.

Our worries are far from over, however. We always have to contend with an enormous amount of paperwork, and bill collectors call us when the insurance company is slow to pay for services. Authorizations for specialists and special services can take days, weeks or months to process. We constantly have to order new supplies. Nurses are often unreliable and do not show up for their shifts. And some of the nurses are not experienced in caring for AJ's special needs.

AJ still lives his life from day to day. Amazingly, aside from his physical problems, he has developed into a normal two and a half year old. He has recently started to walk with a walker and is now off the ventilator when awake. We are very thankful to have our home, our family and our faith.

—Mae T. Moore
Mesa, Arizona

significantly with a more traditional "fee-for-service" payment system. Since doctors receive a fixed per-patient payment, they have a strong incentive to keep patients "healthy"—keeping the amount of medical services provided (other than preventative services) to a minimum. We knew this would be more difficult to accomplish with our patients who had chronic illnesses and special health care needs.

AHCCCS embraced the general concepts of managed care: primary care physicians serving as "gatekeepers," pre-authorization for specialist referrals and non-emergency hospitalizations, the use of formularies (lists of approved medications) to restrict prescription of more expensive drugs if a less costly alternative is available, limited mental health services, the use of home health care in place of hospitalization and payment only for "medically-necessary" durable (long-term use) and disposable (one-time or short-term use) medical supplies, and only in "reasonable quantities." We knew that each of these areas could be a pitfall for our patients with special health care needs—children who were significant users of many of these items and services.

Taking the plunge

We knew that our plunge into the managed care of children with special health care needs would require a combination of hard work and commitment to meeting the needs of our patients. Fortunately, our previous fee-for-service experience and good record keeping provided us with data relating to the ways medical resources were typically used by this population of children. For example, our data showed that children with special health care needs visited the doctor at least twice as often as generally-well children and that these visits often involved more complicated medical problems. In addition, such children were hospitalized about ten times as often as children without special medical needs. We also spent more time on the telephone with their parents—discussing prescriptions, referrals to specialists, school and therapy issues and other health care questions.

Our data clearly demonstrated that quality care for a child with special health care needs would, on average, cost significantly more than provision of the same level of care to a generally-well child. Using this data, we were able to

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negotiate the capitation rate we would be paid by the HMO. As physicians who are used to thinking primarily of meeting patients' needs, we found it difficult to deal with the economic realities of running our practice like a business. However, we knew that unless the HMO paid us enough to cover our expenses, we would not be able to continue to provide comprehensive and quality care.

Whenever it came time to renegotiate our contracts—every one or two years—we were able to utilize data from the *previous* contract period relating to cost of care, frequency of office visits and hospitalizations, severity of illnesses and other services we performed—services not typically reimbursed by health insurance, but that we found to be essential to quality comprehensive care of individuals with special health care needs. These services included case management—the overall coordination of all aspects of patient care, including anticipation of future medical, psychological, social and family needs; preparation of supporting documents enabling children to acquire equipment and receive necessary therapies; attendance at conferences with representatives of schools and state agencies; and, last but not least, attention to the concerns of other family members, as their well-being affects the overall well-being of the child with special health care needs.

Perhaps more importantly, we were able to demonstrate that both patients and the HMO benefited from the concept of a "medical home"—a place where the individual with special needs can get comprehensive, coordinated, family-centered health care.

Coordinating care

Our weekly physician staff meetings soon turned into sessions where we could update each other on our special patients. Each week, we assigned one person to see patients in the hospital and, when necessary, after normal office hours. Before the advent of managed care, we had typically performed hospital rounds early in the morning, before seeing office patients. But now, the person on "hospital duty" for any given week extended those hours to allow for coordination of care with specialists and other case management issues. We also had to make time to deal with school or therapy concerns. We quickly learned that taking care of these issues before problems arose improved the overall care of our patients with special health care needs.

Specialist care—so vital for many children with special health care needs—can be difficult to coordinate under managed care plans, which typically require pre-authorization before payments can be made to the specialist. Usually, specialist referrals consist of a two-step process. First, we seek authorization from the family's private health insurer, if any. Unfortunately, such authorization is often denied because, when it comes to referrals, private insurance companies often rely on decision-making guidelines for generally-well children, who do not require many specialist referrals. Private insurance may also deny referrals for "pre-existing conditions." If denied, we make the referral through the patient's Title XIX or Medicaid HMO plan. In some cases, any treatments, medications, services or medical goods prescribed by the specialist may need to go back to the primary care physician for authorization.

Not surprisingly, this process typically results in a sea of paperwork that must be navigated carefully, by a person who knows the rules and regulations of both commercial insurers and government programs. We do our best to explain these rules to families and, sometimes, to patients' state developmental disabilities case managers. When everyone understands the process, they are less frustrated with occasional delays in seeing a specialist.

Communication among all parties is essential. To be effective case managers for our patients, we must cultivate close working relationships with pediatric specialists. We insist on receiving all our patients' outpatient care plans (such as therapy reports and diagnostic studies). This allows us to ensure that families fully understand the intended plan of treatment.

Treatment plans sometimes include criteria for hospital admission. Knowing the criteria ahead of time can allow us to make alternative plans—for example,

Managed Care: One Mother's View

As the mother of two children with disabilities, I have had a great deal of experience, both good and bad, with managed care. In a way, however, my experiences with the health care system really began as a child. For 100 years, some males in my family have had Lenz anophthalmia, a genetic condition causing them to be born without eyes. My younger brother, my cousin and four great-uncles all had this condition.

When I was growing up in Illinois, in the 1970s, families of children with disabilities had few choices; they either had to place their children in institutions or try to care for them at home without outside assistance. There were no services available for individuals with multiple disabilities. My parents raised my brother the best they could, but eventually they had to send him to a state residential school.

In 1984, my son Andy was born with no eyes, mild cerebral palsy, an enlarged heart and a small kidney. I was shocked, because doctors had told me I was not a carrier of the condition. Although our family had more services available to us than my parents had had with my younger brother, we had to travel far to take advantage of them—five hours to the eye specialists in Chicago and two hours to the Shriner's Hospital in St. Louis. Despite our private insurance coverage and additional help from Illinois' public assistance program, Andy's medical and surgical bills were enormous. Eventually, we had to file for bankruptcy.

While visiting Phoenix, we heard about a special preschool for blind children. Wanting a better life for Andy, we moved to Arizona. We were amazed at the many other services available there, services we needed even more badly when our second son, Matthew, was also born with no eyes and other medical complications.

Our lives have improved because Arizona's managed care system focuses on our family's needs. Case managers track our children's care and provide information on available programs and services. They have helped us find doctors, schools, recreation programs, parenting classes and support groups.

Although I am generally happy with the opportunities and services available to my children, I still see a need for some changes in Arizona's managed care system.

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Tammy Doom congratulates her son, Andy, 5, on winning a ribbon for horseback riding. Andy, now 11, was born without eyes and has cerebral palsy.

Under the present system, for example, it can take months to get a referral to a specialist. It took more than a year to get approval for Andy to receive psychiatric counseling and treatment. It is frustrating to know that specialists and services are available, but because of red tape and paperwork, not readily accessible.

One of my biggest gripes with managed care, however, is that we can only choose a doctor or hospital from a specific list. Suppose we were to have a medical emergency and couldn't get to a hospital that is on the list?

My second major complaint is that managed care organizations pay doctors only so much per year, per child. Children with disabilities and chronic illnesses need more care, and doctors should not have to donate their services or lose money in order to care for them. We feel very lucky to have found Dr. Barela of Phoenix Pediatrics, a compassionate pediatrician who is not afraid to get involved with his patients. Dr. Barela listens to parents and supports their decisions. He helps us locate crucial services and fight for referrals.

The Arizona managed care system has a lot of potential and I believe other states will benefit from using our system as a model. But managed care, even in Arizona, must keep up with society's changing health care needs and be open to improvements.

—Tamera Doom
Phoenix, Arizona

arranging to have certain procedures performed either as an outpatient or in a subacute facility (a smaller facility that is better able to care for chronic conditions that do not change much). This type of care is cost-effective for the HMO, and often is more comfortable for the child and family. Adequate follow-up and monitoring allow our specialist colleagues to be comfortable with outpatient care. Again, good communication is essential.

Home health care also has to be monitored closely, sometimes a difficult task because we don't see a home-care patient on daily rounds, as we would if he or she were hospitalized. But we have developed a close working relationship with the home health agencies in our area and insist on accurate and timely reports on day-to-day patient care. Because we consider home health care agencies an essential part of a patient's "medical home," we welcome their suggestions for improving care and their observations about the status of our patients.

Other issues

• *Formularies*, restricted drug lists, are a special issue with managed care companies. Children with special health care needs typically use different types and quantities of prescription drugs than the general well population. When a child needs a drug that is not listed on the formulary, we must seek special authorization from the managed care company. Based on our recommendations, however, many of the HMOs we work with have expanded their formularies for children with special needs. We have found that it is important to educate the managed care companies—especially their medical directors and pharmacists—about the non-formulary medications commonly used by children with special needs. We also need to justify the increased quantity of certain medications that are often required by children with chronic illnesses. This education process makes subsequent authorizations much easier to obtain, so our patients can get their medications on time.

• *Mental health benefits* are typically inadequate under government programs and commercial health insurance alike. However, mental health and behavioral issues are a significant concern for the families of children and adolescents with special health care needs. Too often, we are told that a child or adolescent with special health care needs—for example, cerebral palsy, mental retardation or autism—cannot also have psychological or psychiatric problems such as depression, anxiety or behavioral problems typical in children without disabilities. But we know these problems exist; we also know that delaying treatment only makes the situation worse, so we have instituted interim behavioral health treatment, using psychotropic medicines when appropriate, while fighting to obtain mental health treatment by an appropriate provider.

• *Durable and disposable medical goods* are often a target for cost savings by HMOs. However, because we know that these goods and equipment are very important to our patients, we institute regular reviews to make sure they are making the best use of their equipment or supplies and to assure the HMOs that the equipment or supplies are still required. If our review shows that a specific piece of equipment or a medical supply is no longer needed, we will not reauthorize it. Parents are an important part of this review process, and we carefully consult with the families of our patients before making these types of decisions. Communication and trust are essential.

• *Physical therapy, occupational therapy and speech therapy* are special issues for children with disabilities because the right therapy at the right time can make a significant difference in the development of these children. Title XIX typically does not cover these services for children older than three, and commercial insurers have other limitations; most cover these services only for limited periods and only for rehabilitative purposes (in situations when a previously-acquired skill has been lost as the result of an injury or illness). However, for children older than three, therapies may be covered by school districts and/or the state division of developmental disabilities.

As primary care physicians, our job is

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to coordinate the therapies no matter which agency is providing them. When parents request more therapy services than their child is currently receiving, we listen to the parents and the therapist, while making our own assessment of how successful the therapy has been or is likely to be. These are difficult decisions to make, but we can't justify spending money for therapy that is likely to be nonbeneficial.

Advantages and disadvantages of managed care

One of the most important potential advantages of managed care for children with special health care needs is greater access to primary care and, perhaps even more importantly, a medical home, in which case management is centralized and always available. The medical home also makes medical records more readily available. Ideally, the primary care physician will notice new medical problems or complications, allowing families and insurers to avoid redundant or unnecessary services. If the medical home works as it should, managed care systems can save money while still providing quality care to children with special health care needs.

One possible disadvantage to families and patients may be the need to switch to new primary care physicians and specialists. This may disrupt familiar patterns of seeking medical care. Families may also experience delays in the referral process because another entity—the managed care organization—stands between the primary physician and specialist. Restricted formularies can also present problems. Sometimes families may feel that doctors have economic disincentives to providing needed services, especially if those services are expensive. This may lead to distrust between physician and parent.

Managed care can also have disadvantages for primary care physicians. One potential disadvantage is the possibility that a physician will end up assuming some of the financial responsibility for caring for individuals with special health care needs, especially when many of the medical costs are beyond the physician's control. The extra paperwork, and the additional employees required to deal with it, is another disadvantage. Data demonstrating the use of medical resources by this special population—and documenting the necessary time and staff commitment—can help doctors negotiate appropriate reimbursement with the managed care organization, thus minimizing these disadvantages.

Whether in Arizona or elsewhere, doctors working within the system face a unique challenge when it comes to including the child with special health care needs in the mainstream of medical care. To do so will require reeducation of both primary care physicians and specialists, as well as managed care companies. Most importantly, we must maintain the concept of a medical home for children with special health care needs. **EP**

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Camp CAMP

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Back in the spring of 1979, Chris Johnson, a pediatric resident at the United States Air Force Medical Center in San Antonio, could have had no idea that performing a routine summer camp physical would change her life. Her young patient, Matt, had had a kidney transplant several years earlier. He also wore leg braces and a back brace. As Dr. Johnson conducted the physical exam, Matt chattered eagerly about the special camp for children with disabilities he was to attend that summer.

In October, when Dr. Johnson saw Matt again, she asked how he had enjoyed camp. Tears welled up in his eyes. "They wouldn't take me," he said softly. "They said I was too handicapped."

The camp required that all children be completely self-sufficient, but because of his back brace, Matt could not reach down to tie his shoes or fasten his leg braces. "Matt was a little boy with great determination. He wanted to be 'normal,' but was not given the chance," Dr. Johnson says. "It was then that I knew I would start a camp. It had always been a dream of mine... but Matt pushed that dream forward."

Chris Johnson dreamed of a camp that accepted all children, regardless of the severity of their disabilities. Her vision became a reality in 1980 when, with a grant from the Air Force Aid Society and the help of private donations, she founded Camp CAMP (Children's Association for Maximum Potential). That summer, Matt was one of 62 children with disabilities and special health care needs to attend a week-long camp session in Center Point, Texas near the Guadalupe River in Texas hill country. Today, children from all over the U.S. and beyond attend the CAMP sessions held each summer from June through August.

A camp experience for every child

CAMP has been true to its original goal of providing a camp experience to any child who wants to attend, regardless of his or her special needs. CAMP accepts many children who could not attend other camps, even special camps for children with disabilities. CAMP campers include children who breathe through tracheal tubes or with the help of ventilators, children who are unable to eat normally and are fed through g-tubes, children with no communication or self-help skills, and children requiring around-the-clock medications.

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CAMP founder "Doctor Chris" says, "As far as we know, it's the only camp of its kind in the country. No one takes the variety of disabilities we do."

From Guilt to Dreams

When I first thought about sending my children to camp, I was thinking of my husband and myself. We had not been alone together since the birth of our oldest child, 10 years earlier. It was time for us to be a little selfish.

I looked for a camp both children could attend; I wanted everything—accessibility, counselors trained to care for children with disabilities, a one-to-one counselor-to-camper ratio and a good medical staff. I chose CAMP for several reasons, not the least of which was the fact that I could never find another camp full of doctors and nurses trained in developmental disabilities. If one of my children got hurt, he couldn't be in better hands.

Like most children going to camp for the first time, my boys were not sure if they really wanted to go. But after we talked about it, they decided it would be fun. Still, I remember crying as we drove away after dropping them off. I had so many fears, or maybe it was guilt. Could my oldest son, who has cerebral palsy, survive without me for six days? Would he eat? Would he sleep? Would he cry? Would he be happy? I didn't worry as much about my four-year-old, because he seemed so independent, but, still, he was only four.

Eleven-year-old Jerad Kratz enjoys a hayride supported by the caring arms of CAMP counselor Nathan Kwan. Jerad, now 13, has cerebral palsy.

While their children were enjoying their first week at CAMP, Linda and Steve Kratz spent some much-needed time alone together in San Francisco.

The next morning, my husband and I left on a five-day vacation. Each night, we called home to get our messages, but there were never any messages from CAMP. Gradually, our fears subsided. We were finally able to relax and have a wonderful vacation.

Although we enjoyed our vacation, we couldn't wait to go pick up the children. I was happy just to see them alive. Everyone laughs when I say that, but when you have cared for a child for 10 years—a child who requires total care—you wonder whether he can live without you or not. It was a bonus to hear about all the fun they'd had!

That first year of CAMP gave me new dreams for my child. He has a very bright future. Yes, he does have a disability, but he is not totally dependent on us. I think that's the best lesson any parent can learn.

—Linda Kratz

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Circle #226

The Other End of the Rope

As a camper at Camp CAMP, I made new friendships—many of which still endure. Now, as a CAMP counselor, I have the opportunity to be at the other end of the rope for a while and give back to my community by helping someone else.

This experience has helped me to learn more about disabilities, including my own disability, spina bifida. One of the most valuable benefits of being associated with CAMP, however, is making new friendships with fellow counselors while educating them at the same time. Also, I now see medical professionals in a new light, having watched how they handle the campers. And I've learned how to deal with a variety of medical situations. Because of CAMP, I have no doubt or hesitations about my plans to become a special education teacher.

CAMP counselor Vanessa Vance, 16, who has spina bifida, lends a guiding shoulder to camper Casey Petri. Casey has a visual impairment and seizure disorder.

The CAMP staff always works as a team to help campers achieve their goals, no matter how small. The counselors then feel good about themselves for the work they've done, and the kids become a little more independent. Two years ago, I had the joy of caring for a camper with a visual impairment and seizure disorder. That was the most fun and rewarding week of my life! My camper and I enjoyed our time together, and she was able to have fun with other kids with disabilities. I liked working with her because she needed me, but she also tried to do things for herself. She was always ready to give me a hug. And when it came time to do things that I couldn't help her with—like washing her hair—she tried harder to do it herself.

—Vanessa Vance

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Parents choose a summer CAMP session based on their child's disability. For example, one session specifically serves campers with mental retardation and seizures; one is set up for children with autism or PDD; another is for campers with multiple disabilities. Ninety to 100 children with developmental disabilities attend each session.

Brother and sister Jonathan and Nicole Reusser share a fun moment in the CAMP pool. Jonathan, who has cerebral palsy, uses an adapted inner tube to support his back.

How can CAMP care for so many children with disabilities and special health care needs? The answer lies with both staff and facilities. In addition to wheelchair-accessible cabins, dining hall, swimming pool, tennis court, classrooms and activity pavilions, CAMP facilities also include an infirmary with 14 beds for 24-hour care. The infirmary's intensive care unit has a well-stocked pharmacy, and is equipped with cardiac monitors, oxygen, intravenous pumps, pulse oxymeters and other equipment necessary for medical emergencies and for the acute care of children with chronic conditions.

The CAMP staff is comprised of doctors, nurses, therapists, teachers and high school and college students—nearly all are volunteers. The staff-to-camper ratio is usually 1:1, but can be as high as 2:1 for children who require constant supervision.

Professionals learn by doing

Many dedicated professionals come to CAMP year after year to provide medical services as well as to work in other capacities—one neonatologist dons the cap of camp chef each summer. But other professionals are attracted to CAMP because of the unique opportunity to "learn by doing." CAMP offers an accredited continuing education course on developmental disabilities that awards graduate school credits and continuing education units (CEUs); health care professionals are required to earn a certain number of CEUs each year to maintain professional certifications.

Professionals spend every morning, and alternating afternoons and evenings, attending classes on specific disabilities, taught by experts in various fields. Outside the classroom, the professionals are divided into teams, each of which is assigned to provide medical care to one group of campers.

By offering this course, CAMP ensures that the camp has adequate medical staff. These professionals leave CAMP knowing how to better care for children with special needs and, perhaps more importantly, with the ability to look beyond wires, tubes and braces to see children with disabilities not just as "patients," but as "kids."

Getting back as much as you give

Most CAMP counselors are high school and college students. "Some of our counselors are former campers and up to 25 percent of them have disabilities," says Johnson. "Some counselors have only physical disabilities, but CAMP is one of the only camps in the United States where some of the counselors have mental retardation."

Upon completion of an eight-day training course prior to the start of camp, these teens know how to deal with seizures and problem behaviors, feed children with g-tubes, lift children in and out of wheelchairs, perform CPR and manage a variety of other situations—but always with the supervision of an on-site medical staffperson. Each counselor is assigned to care for a specific child. The work is difficult, but most counselors believe they get back as much as they give. Vanessa Vance, a 16-year-old counselor with spina bifida,

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echoes the thoughts of many: "CAMP has provided me not only with social skills; it also has given me an education no school can provide." The experience of volunteering at CAMP has such a positive impact on the lives of the counselors that many decide to pursue careers in disability-related fields.

Just like any other camp

Although medical care is always available, the real focus of CAMP is to provide children with a true camping experience. The week is filled with fun activities like archery, riflery, swimming, canoeing, horseback riding, crafts, nature hikes, cookouts, carnivals, puppet shows and dances. Each activity is adapted so every camper can participate. Modified inner tubes allow children like Jonathan Reusser, who has severe cerebral palsy, to enjoy a refreshing swim in the pool. With a counselor riding behind and one walking on either side, a child with severe disabilities can ride a horse—a thrilling experience that also helps improve gross motor coordination.

Sibling Program participant Katelyn Tarwater shows another camper how to give her brother, Ryan, a drink of juice.

Being able to participate in regular camp activities allows campers to see that there are many things they *can* do. Dr. Johnson tells the story of a seven-year-old boy with Down syndrome and heart defects who arrived at CAMP unable to walk or feed himself. "I asked his doctor if there was any medical reason why he couldn't walk or feed himself. The doctor said 'no.' So at CAMP, anytime the boy wanted to swim or do any other activity, he had to try to walk. We also helped him learn to feed himself. When his parents came to pick him up, he ran into their arms..."

Opening the door to siblings

Another unique aspect of CAMP is its sibling program, which

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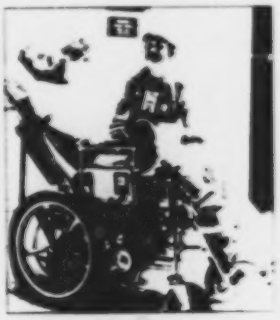
"I can do just about anything!"

In 1988, Dr. Johnson received a call from a parent whose child wanted to attend CAMP. The woman's son, Jimmy, had sustained a spinal cord injury at the C2–C3 level when he was six years old. He had a tracheostomy and breathed with the aid of a mechanical diaphragm stimulator. He also had a backup ventilator, to be used in the event of a stimulator malfunction. Jimmy had received all of his schooling at home via closed circuit TV. Except for trips to the hospital, he had never left the house.

We visited Jimmy, and spent two hours talking with him about his needs and what it would be like at CAMP. We could tell he was frightened and, to be honest, we were somewhat frightened, too. Eventually, however, Jimmy decided to attend our older teen session.

Another nurse and I were assigned to Jimmy. The first night, Jimmy had some difficulties with circulatory problems due to the hot weather. But once we got settled in, Jimmy relaxed and began to enjoy himself.



Jimmy Finch (in wheelchair) came back to CAMP to visit while making a United Way film.

The teen session included a smaller group of campers and focused on teaching independent living skills. We took the teens on community outings to increase their social skills and their participation in regular activities such as ordering food at a restaurant, buying groceries, going to a movie and going bowling. I'll never forget bringing Jimmy to the local pizza restaurant. He was infatuated with the big screen TV and the salad bar. He had never seen anything like them before. Every day, there were hundreds of new things for him to learn and experience.

On the last night of CAMP, it started raining heavily. But even though we could see the water lapping up against a nearby cabin, we had no idea that the river, which was just a few yards away, had risen 14 feet. At 11:30 p.m., the camp owner knocked on our doors and told us that we might lose electrical power. Adrenaline shot through our bodies. We realized that Jimmy had used his battery-powered wheelchair all day and that we had only just begun to recharge it. We would have no electricity for his stimulator!

Ten Marines were at camp to help us in any way they could. Well,

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began in 1990. This program, created partly in response to requests from parents, allows siblings to attend CAMP alongside their brothers and sisters with disabilities. Up to 40 siblings attend each CAMP session, sharing many of the same activities. The "sibs" also participate in their own activities during which they receive positive, undivided attention from CAMP staff members. At bedtime, siblings retire to their own, more rustic campsite away from the rest of camp.

The staff has found that siblings can often provide important information about caring for a brother or sister. Last summer, on the first night of a camp session when a counselor was having trouble feeding a 10-year-old, non-verbal camper, the boy's younger sister came over to help. She told the counselor, "Don't do it that way, do it this way," and, taking the spoon, positioned her brother's head properly and began to feed him. After this demonstration, the boy's counselor was able to feed him successfully for the rest of the week.

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we knew how they were going to help us that night! The Marines, Dr. Chris, the other nurse and I sat around Jimmy's bed with our flashlights, telling jokes and trying to keep Jimmy comfortable. We took turns ambu-bagging him so that he could breathe through the night. At 4:00 a.m., a medical transport helicopter came to bring Jimmy to the hospital, but he was frightened and told the paramedics, "There ain't no way I'm going with you on that helicopter. These people have kept me alive, I feel comfortable with them, and I'm staying right here." So we continued to sit around Jimmy's bed, telling jokes and helping him breathe.

While taking a dip in the pool, George Fox uses an umbrella to shade camper Clark Toledo from the hot, Texas sun.

Finally, at 11:00 a.m. the next morning, the electricity came back on. By then, the river had risen 20 feet. We felt triumphant! We had made it through the night and everyone was alive—especially Jimmy. We didn't know at the time that just a few miles down the road, two busloads of children from a church group had failed to escape the flood.

Jimmy's story doesn't end there, however. Two weeks later, the other nurse who had cared for Jimmy at CAMP attended a production of "Cats" at the Majestic Theater in San Antonio. There, in the audience, was Jimmy! When the nurse approached, Jimmy broke into a big smile and said, "Well, the way I figure it, if I can make it through a week at camp, a flood, and no electricity, I can do just about anything." Jimmy's CAMP experience had given him a new lease on life; he was like a new man.

Jimmy is now an inventor and owns his own company. He has invented a wheelchair and cash register that can be used by quadriplegics. He is also the computer consultant for a chain of retail stores in Texas. He has also been featured in several United Way films.

I've attended well over 30 weeks of CAMP in the past eight years, but the session with Jimmy was my most memorable. It had never occurred to me that a camping experience could change somebody's life so completely. I am happy to have played a role in Jimmy's "rebirth." And I'm sure he has tried every salad bar and large screen TV in San Antonio by now!

—George Fox, RN

Branching out

Since its founding, CAMP has expanded into many other areas of service for local families of children with disabilities. These include Respite Weekends, Parents' Night Out and Teens' Night Out, a child developmental center, a day care center, and educational courses like the Pre-Independent Living Skills Course for young adults with disabilities. CAMP also hosts family retreats and conferences throughout the year.

CAMP campers come from all over the United States. A sliding-scale tuition fee enables families to meet the cost of attendance. Applications for summer CAMP 1996 are due by May 1, 1996. Contact CAMP, P.O. Box 27086, San Antonio, TX 78227; (210) 671-2598 or (210) 671-5169; (210) 671-3290, fax. **EP**

—Kristen E. Holmstrand

Kristen E. Holmstrand is an EXCEPTIONAL PARENT editorial assistant.

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CAMP!

"Gee, Mom, I want to go... back where the toilets flow"

by Arden Miller

The chorus of this irreverent camp song reverberated in the back seat this past summer as we wound our way up the Loyalsock Valley of central Pennsylvania to Camp Lycogis. My daughter and her friends were on their way to Girl Scout camp again.

Three summers ago, my husband and I first debated the merits of overnight camp for our daughter, who was then 11 years old. Amanda, who has mental retardation, attends a regular public school where she is included in social studies and science classes, as well as art, music, gym, computer science and home economics. She goes to a resource room for language arts, math and reading. Her language skills and articulation are poor; even her best friend often asks her to repeat sentences. Her social skills are like those of a younger child, but although her behavior is obviously "different," it is not socially inappropriate. She usually has a sunny disposition. Some tasks frustrate her, but she generally will try something at least once.

Eleven-year-old girls in the Hemlock Girl Scout Council attend camp by themselves or with one buddy, and stay for five nights—without troop leaders or parents. "Is Amanda ready for this type of experience?" we asked each other. And how about the camp; how would staff members handle a child with special needs? The idea of letting Amanda go away for that length of time, without one of us, was more than a little frightening.

Buddies Amanda (left) and Alycia enjoy hanging out at the swimming dock.

But Amanda wanted to go. She had worked hard selling Girl Scout cookies that winter, and had earned "Cookie Dough" credit to apply toward camp tuition. And her younger friend, Alycia, was now old enough to attend the same camp session.

Making plans

We began by contacting the Hemlock Girl Scout Council offices in Harrisburg, Pennsylvania. We spoke with the camp programs coordinator and were frank about our concerns. It was reassuring that she had met Amanda previously at some of the Council-sponsored camping trips in which our troop had participated, and that she would be spending the summer at Camp Small Valley, the camp Amanda and Alycia had chosen. She was honest enough to admit that even Girl Scouts are sometimes unkind to girls who are different, but added that the counselors would be trained to deal with such situations and that the Council could provide the support Amanda would need at camp.

This group of happy campers and counselors at Camp Lycogis during the summer of 1995 included Amanda (far left) and her friend Alycia Lazur (front center in white shirt).

Our packet of camp-related paperwork included a questionnaire in which we could describe our daughter for her counselors. It also asked both parent and child to describe their hopes, dreams and camp expectations. Our questionnaire quickly became five pages of typed information that we hoped would be helpful for the counselors; we gave as much detail about Amanda, both good and bad, as we could. Amanda's section of the questionnaire was brief and to the point—she just wanted to have a good time.

Not perfect, but good enough

That first year, I spent the week of camp watching the clock and worrying about Amanda: Is she happy? (Yes, she was happy.) Is she having a good time? (Yes, she had a *great* time!) Is she making new friends? (No, but her best friend was there with her.) Is anyone making fun of her? (No,

nobody was mean; everyone helped her.) When I finally went to pick her up, she and Alycia talked about camp non-stop the entire way home.

Of course, not everything was perfect. Amanda had a few problems at camp, not the least of which was that she had to use an outhouse, something she despises. A few times she waited too long to go to the bathroom; one time she was afraid to get up at night to go to the outhouse by herself, and couldn't wake up Alycia, so she wet the bed. Amanda and Alycia also hated walking up the hill at camp, but did it because they had to. And after a whole week together, Alycia was a little tired of Amanda. Alycia wanted to be with new friends, while Amanda only wanted to be with her secure old friend.

But after three years of camp, Amanda and Alycia still look forward to each summer's session. They now attend Camp Lycogis, which has flush toilets and no large hills. The counselors there, as at Small Valley, encourage Amanda's independence.

This past summer, we faced a small dilemma when Alycia wanted to have a different buddy at camp. We worried because three girls are not allowed to "buddy together" in the cabins. We solved the problem by inviting another friend, from Amanda's special education class, to be Amanda's buddy. This girl had gone to church camp for two summers, so she was no novice to being away from home. All four girls ended up in the same cabin anyway—much to the dismay of the counselors, as our crew of girls stayed up late laughing and woke up very early giggling. This was the year Amanda learned to laugh silently.

Will Amanda go to camp again this year? You bet! She and her friends have already chosen the camp session they want to attend and are busily planning cookie sales to finance their week of fun. **EP**

After a couple summers at Camp Lycogis, a very nonchalant Amanda is an old hand when it comes to the camp's rope walk.

Arden Miller lives in Selinsgrove, Pennsylvania with her husband, Roy Swazey, and children, Amanda, 14, and Charlie, 9. Arden is a Cadet Girl Scout leader for Amanda's troop and Assistant Cubmaster for her Charlie's Cub Scout Pack. Arden works as a dietitian at a state long-term care facility for adults with mental retardation and/or physical disabilities.

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Elizabeth Monroe Boggs

April 5, 1913 – January 27, 1996

Just a little more than two years ago, I listened to a very thoughtful speech given by Elizabeth Boggs as she received the N. Neal Pike Prize for Service to People with Disabilities from Boston University. Her presentation was vigorous and energetic—urging us all to continue our efforts.

Although many EXCEPTIONAL PARENT *readers may not have had the honor of knowing Elizabeth, I hope that her story, which demonstrates the extraordinary power of one parent, will be as inspirational in print as Elizabeth has always been in person. I suspect she is already conferring with the Powers That Be to improve the quality of life...*

—S.D.K.

On January 27, 1996, the world mourned the passing of a tireless activist in the disability rights movement. Elizabeth Monroe Boggs, Ph.D., 82, died of injuries suffered in a January 21 automobile accident near her Hampton, New Jersey home. Dr. Boggs, often called the "First Lady" of the Association for Retarded Citizens, spent much of her adult life championing the causes of Americans with mental retardation and developmental disabilities.

Dr. Boggs' initial career trajectory was that of an academic. She graduated *summa cum laude* from Bryn Mawr college in 1935, whereupon she began graduate study at Cambridge University in England. There she earned her Ph.D. in theoretical chemistry, and returned to the U.S. in 1939 to accept a research position at Cornell University. She quickly gained recognition as one of America's brightest academic stars. She was held in such high regard, in fact, that the U.S. military asked her, and she agreed, to participate in the secret Manhattan Project, the ultimately successful construction of the atomic bomb.

In 1941, while still at Cornell, Elizabeth married Dr. Fitzhugh Boggs, a fellow scientist. Four years later, their son, Jonathan David, was born. While still an infant, David suffered a serious illness that left him with brain damage. David's mental retardation first focused Dr. Boggs' attention on the care and treatment of children with disabilities. She took courses in special education and organized small groups of parents within various communities, but also sought to create an association with a more national focus. In 1950, she co-founded the Arc, then called the National Association for Retarded Children. She became a full-time public advocate two years later, after making the difficult decision to place David in a residential center.

Dr. Boggs became a recognized authority on public policy for people with disabilities, authoring key pieces of legislation and advising policymakers for the better part of four decades. She crafted the United Nations Declaration on the Rights of Mentally Retarded Persons; she helped to design the Supplemental Security Income program; she wrote and agitated for adoption of the Developmental Disabilities Act; and, working with activist Justin Dart, she helped to shape the focus of the Americans with Disabilities Act (ADA). President Kennedy appointed her to his Commission on Mental Retardation, and later, she was a member of the President's Committee on Mental Retardation. After serving in an official capacity under four different presidents, she was awarded the Distinguished Service Award by President Bush.

Not only did Dr. Boggs create and lobby for several key pieces of legislation, she also increased the breadth of existing laws and services. She was able to change the legal definition of "disabilities" to include physical disabilities, where before it had referred only to mental retardation; thus, an entire new group of people became eligible for federal assistance. She transformed a New Jersey state agency, which she headed, from the Division of Mental Retardation to the Division of Developmental Disabilities—again, achieving the goal of providing assistance to more people.

The lasting effects of her efforts in Washington and around the country are vast. Without the legislation drafted by Dr. Boggs, many individuals with disabilities and their families would have gone without needed assistance. "Long after the pyramids of the Pharaohs have crumbled to dust, her existence will survive, flower and multiply in the quality of the lives of millions of human beings," said Dart.

A brilliant, compassionate, focused woman, Dr. Boggs gave up an extraordinary academic career, choosing instead to help improve the lives of Americans with disabilities and their families. Such a sustained dedication to an altruistic goal is rarely seen in any era. As President Clinton's letter of condolence to friends and family states, "Elizabeth Boggs represented the best of America... she made it her life's work to ensure that every human being is treated with dignity." We celebrate her endeavors, applaud her triumphs, mourn her loss, and honor her life through our continuing efforts to achieve her goals.

Elizabeth Boggs is survived by her son, Jonathan David Boggs, who resides at the Hunterdon Developmental Center in New Jersey, her niece, Pamela R. Monroe, and her nephew, AnTony Monroe. Memorial celebrations of Elizabeth Boggs' life and contributions are being planned for the early spring, with one event to be held in New Jersey, and a national event to be held in Washington, DC. **EP**

& Youth

CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

Within Reach:

Teens With Disabilities Get Around

Ask a 15-year-old what it means to be 15 and you'll get the answer: "Next year, I'll be able to drive." Driving means independence for a teenager. For teenagers with disabilities, driving first, but also the ability to use transportation services independently is the dream; sometimes realizing this dream is the most arduous transition to adult life.

by Chad Pierro

What is an everyday routine for many people in the United States, something that most don't even think about as time wears on, is the privilege of operating a motor vehicle. Just stepping into a car and going is taken for granted. For most drivers, the largest stumbling block is misplaced keys.

For a teen with disabilities (mainly, but not exclusively, physical), getting behind the wheel takes considerably more planning than for their peers. Each youth faces a lengthy process that involves evaluation, testing, adaptations, and sometimes a long period of experimentation to see what is going to work best for each individual. Training programs can evaluate a teen's ability to drive in addition to identifying the adaptive equipment that will enable a teen to drive. Technology has come a long way. Adaptations include: simple hand controls, low-resistance steering wheels, adjustable driver's seats, touch ignition pads and gear shifts, just to name a few. Depending on individual needs, a car, van, or truck can frequently be turned into a totally different vehicle, perfect for a driver with a disability.

For me, the process began 10 years ago with a trip to Courage Center's Driver's Assessment and Training Program in Golden Valley, Minnesota. Here, an instructor led me through a series of questions and tests, the most memorable being a driving simulation. In this simulation, I was placed in a chair with hand controls attached while watching a film of a small town neighborhood that I was "driving" through. Different situations arose during my journey such as a child running out in the street to get a ball that had rolled in front of me, and I had to react according to each situation. It was a good opportunity to practice driving without being in an actual car. It was a bit difficult to think of myself actually driving a car in such unusual circumstances but it got easier as I went through my "drive."

All drivers have to undergo a sort of driving education program before they are given a drivers permit or license. Like most of my peers, after the Courage Center program, I completed the standard driving instruction at my high school. Like my peers, I saw countless accident films as well as all the ways a crash-test dummy can be dismantled. While this experience showed me what can happen to someone behind the wheel, it did not dissuade me from finishing the course, going through behind-the-wheel training, and taking the license test.

The differences between my high school program and the Courage Center program were several. At Courage Center, I was in a class of one and was basically evaluated on physical grounds. Would

Within Reach
Turn to page 76

DEFINITION

Mobility...
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From page 75

I be able to drive? What sort of adaptations would I need to get for my car? Did I have good reaction time and sufficient motor skills? These questions were answered at Courage Center. At high school, it was a bit more academic and eventually more realistic. I began watching films and taking quizzes and got to the point where I was driving my car sitting alongside my behind-the-wheel instructor (who was not overwhelmed with joy that he didn't have the standard passenger side brake provided in all the school's student driver vehicles).

Major automobile companies are now able to design cars, trucks, and vans to meet individual customer needs. Whether it be a chair lift or adjustments to steering resistance, all these adjustments can be made at the factory with good reliability. Even if the factory is unable to make specific adaptations, local dealers know of alternatives. There are also a number of agencies to contact about funding and maintenance if these are an area of concern (specifically, the Department of Rehabilitation Services knows of funding strategies and agencies who can provide adaptive resources).

The adaptations allowing me to drive had to be made to one of my family's cars. Hand controls similar to the one's I had used at Courage Center were installed. Some drivers require adaptations that involve restructuring the foot controls of the gear shift.

There are many opportunities for teens to learn to drive—don't dismiss the idea before looking into the options. The teenage years are trying enough, but for a teenager with a disability, getting over some of these times can be especially difficult; learning to drive can give control to a teenager who may not have had opportunities to really control her or his own life direction.

Today, programs like Courage Center's are in place or in development around the country. But for those areas that do not have programs available locally, sometimes independently run driving education programs are able to accommodate a prospective driver with a disability once vehicle adaptations have been made. This kind of support can really set the momentum toward a driver's license in motion and it is most often a good alternative.

WRITER

Chad Pierro earned his B.A. degree in journalism at Augsburg College and is a free lance writer in the Twin Cities.

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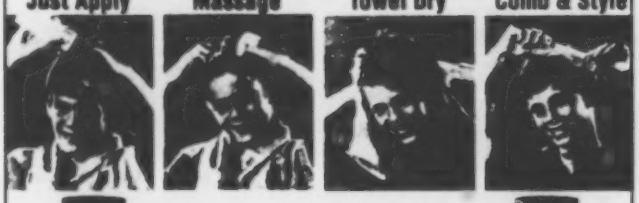

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FOCUS ON PREMATURITY

Applying Research to Intervention

by Robert Perelman

While all parents wonder what the future holds for their newborn babies, parents of premature infants, who often begin life with some "medical complications," are often faced with very specific, complex concerns about the future for their baby (or babies, in the case of multiple births). Initially, both parents and professionals want to know whether a baby will survive, what interventions will be required, and how long-term growth and development will proceed. Unfortunately, even with advanced, sophisticated diagnostic instruments and tests, the medical team cannot make specific predictions about outcomes for many premature infants.

Because the use of today's technology results in, at best, imprecise predictions of a baby's future development, families and physicians must make important life decisions with considerable uncertainty. Physicians attempt to identify "risk factors"—physical symptoms which, in general, seem related to future development difficulties—however, the presence of one or more "risk factors" in any given baby does not allow the medical team to make specific predictions about that child's future with confidence.

Cranial ultrasound: High tech with limitations

Cranial ultrasound (CU) examinations, which are often performed during a premature baby's first day of life, provide a way to determine the presence of brain injuries or abnormalities. CU examinations, which look "inside" a baby's brain, can identify certain abnormalities more accurately than examinations based on observations of the baby from the "outside." Because this technology is a major advance in the diagnostic process, many parents and professionals have high expectations about its ability to help doctors make accurate predictions. However, CU abnormalities statistically associated with abnormal outcomes may not prove to be valid predictors for individual children. For example, a child with moderate CU abnormalities may develop normally, while another infant with only mild CU abnormalities may not develop normally.

A recent study, reported in professional journals, illustrates the imprecision of this tool. The study, funded by the National Institutes of Health, included 1,100 premature babies with birth weights ranging from 1.1 pounds (501 grams) to 4.4 pounds (2000 grams). All the infants were given a CU examination within their first days of life. Of the 901 babies who survived, 777 were observed two years from their expected due date. The follow-up examination assessed the children for a possible diagnosis of cerebral palsy, focusing on "motor skills," such as the ability to walk. However, the study did not include assessments for hearing, vision or intellectual disabilities. The results showed that CU abnormalities can increase the likelihood of an accurate prediction regarding certain outcomes, however, precise predictions could not be made.

One problem with this study, and others like it, is that they do not compare the relative value of different kinds of therapeutic interventions for premature infants. Studies of premature babies that follow each child for a longer period of time would be more useful. Such studies would help parents and professionals identify the most useful intervention strategies for different types of brain injury and may lead to more accurate predictions.

Unfortunately, in today's political climate, many researchers are deeply concerned about the future of funding for such important research. Yet the continuation of such research is critical to parents, doctors and health care policymakers. The results of this research can help parents and professionals make more informed decisions on short- and long-term interventions for individual infants. Such research can also help policymakers make better decisions about health care resource allocation. **EP**

This is the first in a series of articles to be prepared in collaboration with the National Perinatal Association (NPA, 3500 E. Fletcher Ave., Ste. 209, Tampa, FL 33613-4712; 813/971-1008; 813/971-9306, fax). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time-of-birth) health issues from preconception through infancy. The organization fosters optimal perinatal care by promoting education, supporting research, influencing national priorities and encouraging collaboration among all concerned constituencies, including health care providers and consumers. Robert Perelman, M.D., is current NPA President and an associate professor of pediatrics at the University of Wisconsin at Madison.

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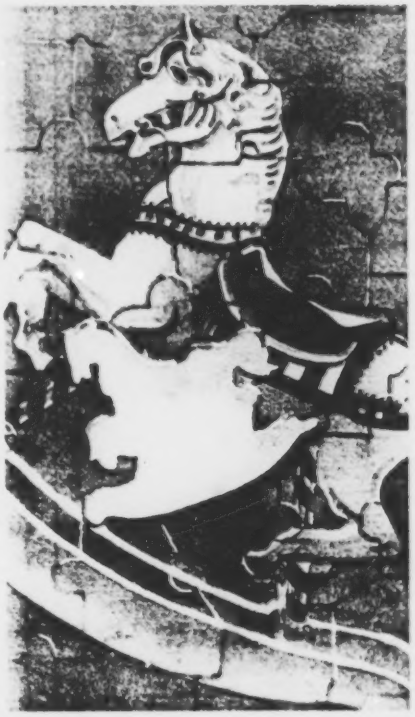

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Circle #287

HEALTH INSURANCE TROUBLESHOOTER

by Richard Epstein

Success Stories

No matter how hard a family tries to provide appropriate health insurance coverage for a child with a disability, there are times when the system just doesn't seem to respond. Sometimes, the only options left are an attempt to change the rules (or their current interpretations), or to negotiate directly with government officials and/or insurance companies. Although both options require a great deal of time and energy, these actions can lead to successful problem resolution and may also establish a precedent, making it easier for others to solve similar problems in the future. In this month's column, I'm happy to share two stories of parents who bucked the system to resolve major health insurance problems.

Developing a Medicaid waiver

Earlier this year, a mother wrote to me about her family's situation: "When my son was 18 days old, I awoke to find him, in his cradle, not breathing and blue. He spent the next four days in intensive care. We left the hospital with a monitor and night nursing care. He was home for only one and a half days before he stopped breathing again. He was admitted to the hospital once more, where they did every test imaginable but were unable to find the cause of the problem.

"We didn't realize that the struggle to keep him alive would also mean a continual battle to get the things he needed. Our first inkling of the struggle that lay ahead came when our son's doctor ordered resuscitation equipment for our home, and the insurance company refused to cover it. Then the company terminated his night nursing coverage; my husband and I began taking turns doing 'awake shifts.' We applied for SSI and Medicaid, but they said we made too much money. In addition, neither program considered apnea, in itself, a coverable 'condition,' even though it was life-threatening.

"Following several hospitalizations, my son was released from the hospital with 30 days of approved night nursing care. He came home with a monitor, a suction machine, oxygen and resuscitation equipment and a positive airway pressure machine.

"After extensive negotiations, the insurance company agreed to cover nursing care on a month-to-month basis. So, every month, I wait for them to terminate this coverage. I'm continually on the phone, and going to agencies trying to find some help..."

Since this family's private insurance program was self-funded, it was regulated under ERISA—the federal "Employee Retirement Income Security Act" of 1974—not under state law. As a result, the state insurance department was unable to help. The family went through a number of insurance company appeals and hearings with the state Medicaid program. Finally, with the help of the state's Protection and Advocacy Service, the family met with state legislators and Medicaid representatives to try to change the rules.

As a result of these actions, the family's private insurer agreed to pay for 120 hours of home nursing care annually. And the state Medicaid program developed a special "In-Home Model Waiver" (to federal Medicaid regulations), which allows the state's program to cover the cost of nursing care in this kind of situation. (In order to deal with the issue of family income, eligibility determination for this waiver considers only the *child's* income.)

Coverage for autism-related therapies

The second case involves a girl with autism, who was insured through her family's self-funded health insurance plan. Her therapies were covered under the policy's provision for "mental retardation, psychiatric or nervous disorder," which had a lifetime limit of 25 treatments (a situation similar to that described in my July 1995 column, "Self-Funded Insurance Plans").

"Our daughter had been evaluated as very high-functioning with no retardation," the parents wrote, "and has never seen a psychiatrist. Autism is not a psychiatric or nervous disorder, but a neurological or neurobiological disorder, and therefore treatable under the policy's general medical provisions."

The family hired an expert attorney and used several expert witnesses in the appeal. The process took more than two years. "We not only fought this issue for our daughter," the parents wrote, "but in hopes it would help other parents."

The case was settled before trial, with the insurance company agreeing to classify autism as a neurological/neurobiological disorder and to cover autism-related medical expenses under the general medical provisions of the policy.

Hard work and determination

These stories demonstrate that hard work and dedication can lead to success in many cases, even those that appear hopeless at first. They also illustrate the importance of working with parents' groups, advocacy groups, expert doctors and attorneys, legislators and Medicaid officials. We obviously need national health insurance reform that will more effectively meet the needs of children with disabilities. But in the meantime, we need to continue trying to solve existing problems on a case-by-case basis, using every resource at our disposal. **EP**

In this column, Richard Epstein answers readers' questions about health insurance. Send your questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number. Only your initials and state will be published. It is not possible to respond to letters individually.

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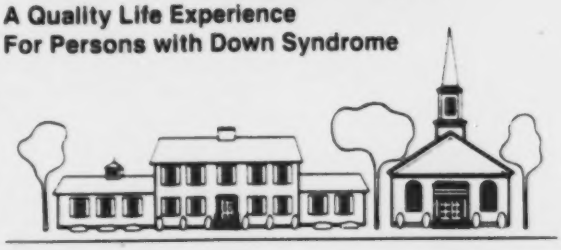

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Circle #99

ASK THE DOCTOR

by David Hirsch, M.D.

ADD and Mental Retardation

Q Our son, now 12 years old, has mild mental retardation (a tested IQ of approximately 65, which psychologists classify as "educable"). He has always been in special education classes and seems to have done reasonably well. But recently, his teachers have told me that his work and attention are not as good as they could be. They feel he has attention deficit disorder, but they do not feel he is "hyperactive." They told me he might do better if he were put on Ritalin and recommended that I have him evaluated for an attention deficit condition.

Is this type of testing worthwhile? My concern is that an evaluation may be inaccurate because of our son's mental retardation. His father and I certainly do not want him on medication he does not need. If he is diagnosed with ADD, what other treatment options exist? Are there alternatives other than drugs?

A Attention deficit disorder (ADD) and attention deficit hyperactivity disorder (ADHD) may affect up to five percent of all American school age children. Attention deficit disorders are thought to be the leading cause of school failure and underachievement. They are characterized by significant attentional weaknesses, impulsivity and, in the case of ADHD, hyperactivity. Secondary traits may include learning problems, poor peer relations and low self esteem.

Treatment options

A significant amount of research has been done on attention deficit disorders, but most studies have specifically excluded children with mental retardation. I agree with your concern that an evaluation of your son may be complicated by the difficulty of differentiating between behaviors indicative of ADD/ADHD and behaviors that are sometimes seen with mental retardation. When I have dealt with similar situations—when ADD/ADHD is considered a possibility, but the diagnosis is not straightforward because of other medical or psychological conditions—I have had a more comprehensive evaluation performed by pediatricians or psychologists with a strong background in development and behavior.

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT'S Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (fax).

More information about ADD/ADHD may be obtained from the following sources:

- **AD-IN: Attention Deficit Information Network,** 475 Hillside Ave., Needham, MA 02194; (617) 455-9895
- **CHADD: Children and Adults with Attention Deficit Disorders,** 499 NW 70th Ave., Ste. 101, Plantation, FL 33317; (800) 233-4050; (305) 587-4599 (fax); http://www.chadd.org/
- **CHADD—Canada,** 1376 Bank St., Ste. 214; Ottawa, ON Canada K1H 7H3; (613) 731-1209; (613) 731-1014 (fax); http://magi.com/~anthonyp/chadd.html
- **Challenge,** P.O. Box 488, West Newbury, MA 01985-0688; (800) 233-2322; (508) 462-0495 (voice/fax)
- **National Attention Deficit Disorder,** P.O. Box 972, Mentor, OH 44061; (800) 487-2282; (216) 255-0422 (fax).

If your son is diagnosed with ADD, it is important to remember that the use of medication should be only one part of a coordinated treatment plan that includes medical, psychological and educational intervention, as well as behavior management.

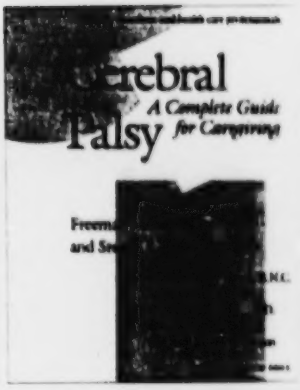
Psychostimulants (medications that stimulate various areas of the brain) are the most commonly used medications for ADD/ADHD. They include methylphenidate (Ritalin), probably the most widely-prescribed psychostimulant; dextroamphetamine (Dexedrine) and pemoline (Cylert). Optimum dosage varies from child to child, and regular monitoring is required. The most common side effects of psychostimulant medication are loss of appetite, poor weight gain and insomnia (all of which are rare in my experience).

A 1990 study performed in Pittsburgh concluded that children with mental retardation and ADD/ADHD respond to methylphenidate in the same way as children with ADD/ADHD who are not mentally retarded. The researchers in that study noted that 75 percent of the individuals with mental retardation and ADD/ADHD who were given methylphenidate (Ritalin) showed significant increases in work output, on-task behavior and attention. However, the attentional gains did not lead to improvement in learning; nor did the researchers find significant increases in appropriate social interactions.

Antidepressants—such as nortriptyline (Pamelor) and desipramine (Norpramin), among others—have also been used to treat ADD/ADHD when psychostimulants have been ineffective or have caused side effects. More recently, clonidine (Catapres) has also been used, especially in individuals with ADD/ADHD who also have certain behavioral, psychiatric or medical problems.

Over the years, various individuals have proposed a number of "non-drug treatments" for ADD/ADHD. These "treatments" have included megavitamin and mineral supplements, additive-free diets, the suppression of yeast growth in the digestive system and, most recently, "EEG biofeedback." Although there have been anecdotal reports that one or more of these treatments have been useful, these reports of success have not been based on scientific evidence. Parents need to be extremely cautious about questionable and unproven treatments. **EP**

Written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute in Wilmington, Delaware, CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING addresses the many complexities and uncertainties related to this diagnosis. At the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications to wheelchair maintenance and dental care. The book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt.



Protecting the Caregiver's Back: Basic Body Mechanics

Many tasks involved in caring for a child may place the care provider's back at risk for injury. Most of these tasks involve performing the activities of daily care, such as dressing, bathing, feeding and moving the child. This section describes good body mechanics that can be used by the care provider to decrease the risk of back injury.

DRESSING

• *Newborn to age 3:* Use a surface that is at a comfortable working level, such as a changing table. The parent should not be forced to lean over the surface in order to dress the child. The crib surface should also be at a comfortable level (keeping in mind that the mattress must be lowered when it is anticipated that a child will soon be standing up), and the crib mattress may provide a good surface for dressing the child.

• *Ages 3 to 10:* If the child is able, he ought to be encouraged to stand up and hold on to furniture while being dressed. This is good therapy and movement toward an adult style of dressing, and allows the child to be dressed with less lifting than is necessary when the child is dressed lying down. If the child must be dressed lying down, and the child's bed is used for dressing, then the mattress surface should be at a comfortable level for the parents to work. This can easily be achieved by placing the bed on blocks, but care must be taken to use side rails so that the child does not fall out of a high bed. If the bed is on the floor, the caregiver ought to place one or both knees on the floor rather than bending over from the back.

• *The older child and teenager:* The same rules apply, but at this age, because of the child's larger size, it is especially important to dress her while she is standing, if at all possible.

BATHING

Bathing is an activity that can involve a great deal of lifting and bending over in positions that can be very stressful to the caregiver's back. Before bathing a young child on a changing table, the caregiver should adjust the level of the table to the level of the caregiver's mid-abdomen. Children from age two to age 10 especially enjoy being bathed in warm water and usually are bathed in a bathtub. There are several different kinds of bathing chairs that provide trunk support for the child who has poor trunk control; an occupational therapist can help you select one that is appropriate for your child. The main problem in tub bathing for caregivers, however, is lifting the child into the bathtub. Before she reaches about age 10, this may be difficult but can still be managed; after age 10, it becomes more difficult. Whenever possible, the child should be lifted or helped into the tub in a standing position; then she can sit down from the standing position. This is much easier for the caregiver. Also, if the caregiver sits on the edge of the bathtub with one foot in the tub before lifting the child, this reduces the stress on the caregiver's back. For the child who can stand, use a shower with a hand rail for her to hold on to. This is an excellent way to bathe an older child who can stand.

As the child approaches puberty and adult height, it is no longer wise to continue to lift her into a bathtub. This is hard on the caregiver's back and usually is unsafe for the child, because there is an increased risk that the caregiver will slip and drop the child, who has become heavier. If she will continue to be bathed in a bathtub, a mechanical lift device that attaches to the bathtub or the ceiling should be used. She can also be wheeled into a shower if the proper home modifications are made. There are a number of different shower chair alternatives. Ask your child's occupational therapist to evaluate the child and determine the best way for her to be bathed—that is, the best way for the child, the care provider and the housing situation.

MOVING

The small infant and child is primarily moved about his environment by being carried. As the child grows but does not begin to walk, caregivers must begin to protect their backs and not simply continue to carry the child

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until they are physically unable to do so. This requires planning for a home environment that is accessible to a wheelchair; planning should take place when the child is between the ages of four and eight. Another option is to use a rolling stool and push yourself, with the child on your lap, along the floor; alternatively, if the child can hold on securely to the stool, he may be pushed along alone. This will only work if the house is not carpeted, however.

As the child gets bigger, transferring from bed to wheelchair becomes difficult. If he might be capable of bearing his own weight so that standing transfers can take place, this needs to be encouraged even at the age when the child is still small enough to be lifted. If you wait to start doing standing transfers until he absolutely cannot be lifted, then it's harder for both the child and the caregiver to learn the technique, and it's much more anxiety-provoking. Both of these factors make it more likely that attempts to learn the technique will be unsuccessful. If a child cannot bear weight and is to be cared for by one adult alone, then mechanical lifts are usually needed to improve the safety of the transfers and to protect the caregiver's back.

Feeding

Most infants are fed while being held by the caregiver. By nine to 12 months, however, the child should be fed while sitting in a seat, with the caregiver doing the feeding while sitting in front of the child. This frees both arms and allows the caregiver to position herself at a comfortable height and have a better view of how the child is doing.

General Guidelines for Protecting Your Back

1. Always get your body as close as possible to the child before starting to lift her.
2. Whenever possible, lift by bending the knees, not by bending through the back.
3. When working standing up, adjust the work surface and the child so that he is at the level of your navel (mid-abdomen); don't bend over while bathing or dressing him.
4. When working sitting down (while feeding the child, for instance), the child's face should be almost even with yours when you sit up straight. This prevents you from slouching over and putting strain on your spine. **EP**

Excerpted from Cerebral Palsy: A Complete Guide for Caregiving by Freeman Miller, M.D. and Steven J. Bachrach, M.D. (with Marilyn L. Hoos, R.N.; Linda Duffy, P.A.-C.; Douglas T. Pearson, Ph.D.; Rhonda S. Walter, M.D. and Joan Lenett Whinston). Published by The Johns Hopkins University Press, 1995.

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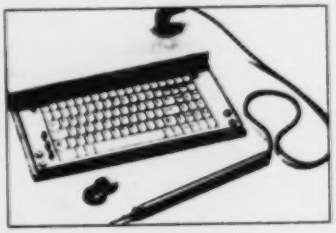

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Circle #61

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Circle #156

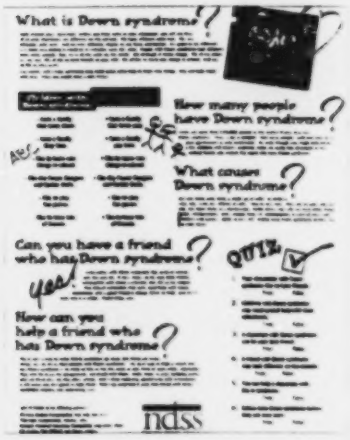
WHAT'S HAPPENING

Publications

• Two new publications offer insights about Prader-Willi syndrome: *The Child With Prader-Willi Syndrome: Birth to Three* describes characteristics of and suggests goals for each developmental level of the young child with Prader-Willi syndrome. Single copies are $6 (includes shipping and handling).

Prader-Willi Syndrome: A Guide for Parents & Professionals provides accurate, current information for families of children with Prader-Willi syndrome. The booklet presents a short review of clinical features, behavioral findings and genetic studies. It also suggests how this information can be used to enhance the lives of individuals with Prader-Willi syndrome. Single copies cost $8.50 (includes shipping and handling).

Both booklets can be ordered from Prader-Willi Perspectives, 40 Holly Ln., Roslyn Heights, NY 11577. Special prices for bulk orders are available. All proceeds benefit the Prader-Willi Foundation, 223 Main St., Port Washington, NY 11050.


What is Down syndrome?
How many people have Down syndrome?
What causes Down syndrome?
Can you have a friend who has Down syndrome?
yes!
QUIZ
How can you help a friend who has Down syndrome?
ndss

• The "Down Syndrome Teaching Poster" is available free to educators and parents to help teach students through grade 3 about their peers with Down syndrome and other developmental disabilities.

continued on page 91

Coming in Late October or November EXCEPTIONAL PARENT at Disney World AND YOU'RE INVITED!!

Encouraged by your responses to the note in *Editor's Desk* in the October 1995 issue, we are beginning to plan for a fun family trip to Walt Disney World in Orlando, Florida, in late October or November, as part of our 25th Anniversary celebration. We want as many of our readers and their families as possible to join us.

We are planning this exciting event in collaboration with the experts in travel planning for individuals with disabilities at AccessAbility Travel, a division of FPT Travel Management Group, Cambridge, Massachusetts. To move ahead with our plans, we need to hear from readers who are very interested in participating; and we need information about the special needs of your family members.

EXCEPTIONAL PARENT Disney World Survey

Interested? Please complete this survey and return it at once, or call (800) 382-0206 (voice) or (800) 228-5378 (TTY) to express your interest. Based on your input, we will plan our itinerary and keep you informed on the pages of the magazine. Please be assured that completing this survey does not obligate you in any way. To discuss your ideas and questions, please contact Judith Perry, director, EXCEPTIONAL PARENT Disney World Celebration, AccessAbility Travel, 186 Alewife Brook Pkwy., Cambridge, MA 02138-1102; (800) 382-0206 (voice), (800) 228-5378 (TTY), (617) 661-3354 (fax); jap@fpt.com (e-mail).

Name (please print) _____

Mailing address (please print) _____

City _____ State _____ Zip _____

❑ Yes, we want to join the celebration at Disney World in Orlando in late October or November

Our group will include: _____ adults _____ children

Special needs (please check)

❑ transportation (to and from events)
- ❑ van rental ❑ auto rental ❑ regular bus ❑ special bus

❑ mobility
- ❑ manual wheelchair, stroller ❑ power chair ❑ wheelchair maintenance & repair

❑ sign language interpreter

❑ special medical technology
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❑ incontinence ❑ need special bed (please describe)_____

❑ special seating needs (please describe)_____

❑ special eating needs (please describe)_____

❑ other special needs (please describe)_____

Besides Disney World, we are also interested in enjoying the following attractions:

❑ Sea World ❑ Universal Studios ❑ Wet N' Wild

Your suggestions_____

On the list below, check those activities that would be of interest to you and your family:

❑ networking opportunities for parents ❑ educational programs for parents

❑ meeting with EXCEPTIONAL PARENT staff members ❑ programs for siblings

❑ adaptive sports ❑ organized social programs for children/ teens

❑ exhibits of adaptive mobility equipment ❑ exhibits of computer equipment

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continued from page 90

The poster stresses acceptance of those who are different and can be ordered from the National Down Syndrome Society, 666 Broadway, New York, NY 10012; (800) 221-4602.

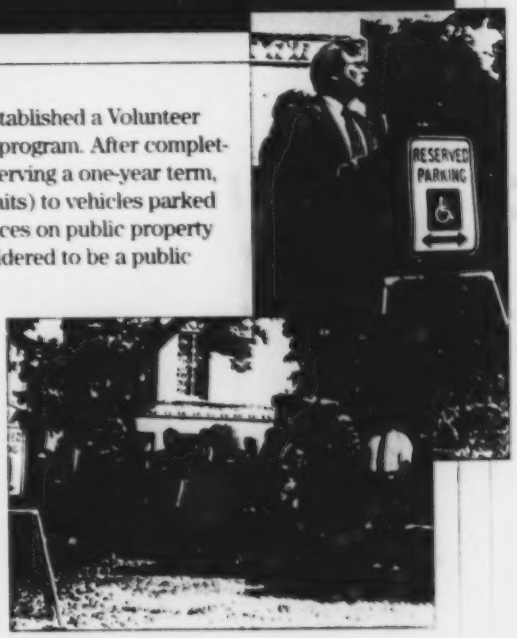
• *Learning Through Listening—An Informational Guide for Students with Learning Disabilities* and *Learning Through Listening—An Informational Guide for Educators and Parents of Students with Learning Disabilities* are free booklets available from Recording for the Blind and Dyslexic (RFB&D), an organization that loans out recordings of academic and professional books to people with disabilities. The guides explain how to borrow and return tapes from RFB&D and also provide tips for listening and notetaking. To request these publications in print, on audio tape or on computer disk (IBM or Macintosh), call RFB&D at (800) 221-4792; (609) 987-8116 (fax).

New Parking Police

The city of Austin, Texas has established a Volunteer Disabled-Parking Enforcement program. After completing training, 20 volunteers are serving a one-year term, issuing citations (within city limits) to vehicles parked illegally in disabled-parking spaces on public property or private property that is considered to be a public accommodation. Bruce Elfant, Travis County Constable, hopes the program will act as a deterrent so that "a year from now all people will have equal access to our businesses, agencies and parks."

Austin's volunteer program was created under city and state disabled-parking laws. Establishing a program in other states would require the support of the state legislature to give it authority.

—Amanda Young



Constable Bruce Elfant officiates at the swearing-in ceremony for the Volunteer Disabled Parking Enforcement Program in Austin, Texas.

Circle #43

LIVING AND LEARNING IN THE COMMUNITY

With its unique model, The Evergreen Center has a history of successfully transitioning students to less intensive community settings.

Evergreen students live in actual community settings traveling to and from school each day through the Blackstone Valley (MA) countryside. With trained professionals, they learn basic skills in the classroom, in the community and in their residence.

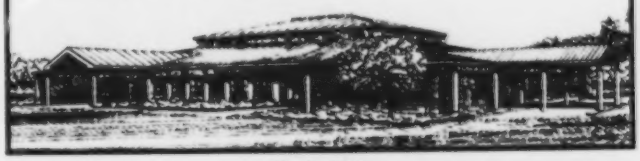
Students receive vocational training and experience real work opportunities. Students are supported with behavior development programs, medical and family services, and physical, speech, or occupational therapy.

Our Students' Challenges

- Autism
- Mental Retardation
- Physical Disability
- Hearing/Sight Impairment
- Severe Maladaptive Behavior

The Evergreen Center is a licensed, private, non-profit residential school offering students and their families from across the country and abroad residential programming 12 months a year. For more information call or write Robert F. Littleton, Jr., Executive Director.

EVERGREEN CENTER
345 Fortune Blvd., Milford, Massachusetts 01757
1-508-478-5597



Circle #131

NEW PRODUCTS

CONVAID 4MX CRUISER

The Convaid 4MX Cruiser is a lightweight, mobile positioning system for children aged five to twelve. The Cruiser uses the child's weight to fully open the chair, eliminating seat slump and preventing accidental folding. It is available in a choice of six colors and offers optional 12-inch rear wheels and pneumatic tires for heavier outdoor use. A transport model, which has been crash-tested for bus or van tie-down use, is also available.

Convaid Products, Inc., Palos Verdes, CA 90274

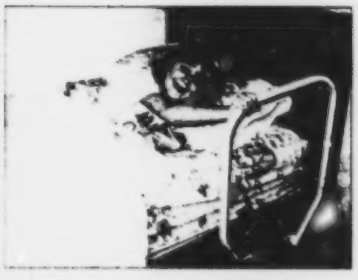
Circle # 195

THE ROCKET STANDER

The Rocket Stander is a mobile standing aid that provides precise postural support and variable angle adjustability. It also inverts to maintain the child in postural drainage. The Rocket Stander is offered in two sizes, with a variety of component options, and folds for easy storage.

Mulholland Positioning Systems, Santa Paula, CA 93061

Circle # 196



BED BAR

The Bed Bar is designed to provide barrier-free assistance for those who have difficulty getting in and out of bed. The grab bar assists with balance and proper positioning, and is available in models to fit hospital and conventional beds.

Brown Engineering, Westhampton, MA 01027

Circle # 197

COZY ME

Cozy Me provides padded protection for youngsters riding in shopping cart seats. The pad features leg openings and a waist strap to keep the child in the proper position and prevent sliding. The colorful vegetable print is suitable for both boys and girls, and the machine-washable pad can double as a changing surface.

Happy Baby Products, Santa Barbara, CA 93105

Circle # 198

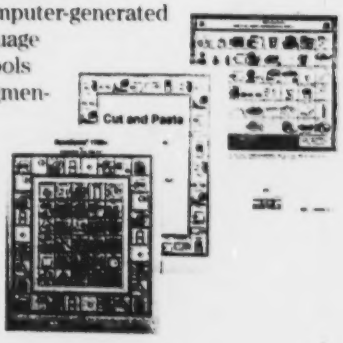
WHIRL-O-WHEEL

The Whirl-O-Wheel is a mobility aid designed to promote independence and to improve dexterity, coordination and upper body strength. The vehicle is propelled using two large front wheels. It can turn 360 degrees in place, and it fits through narrow doorways. Whirl-O-Wheel is available in child and adult sizes. Some assembly is required.

Flaghouse, Mount Vernon, NY 10550

Circle # 199

POPPIN'S DYNASYMS



Poppin's DynaSyms are computer-generated collections of symbolic language pictures based on the symbols used with the DynaVox augmentative communication device. The pictures are divided into 15 categories and are offered in books of 1000+, 1700+, starter packs, classroom packs and sampler packs. DynaSyms include both color and black-and-white pictures. Choose from sticker or plain paper cut-and-paste formats.

Poppin and Company, Arlington, VA 22205

Circle # 200

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 125) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices, or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

Marketplace

IT'S NOT HOPELESS!
School, Behavior, Social Skills. All Types of Disabilities. FREE 20 min. consultation. **Paynter Educational Partners** (800) 555-6519.

HUGE DEMO EQUIPMENT SALE
Wheelchairs, Walkers, Strollers, Hand Cranks, Cycles
Save up to 80% off retail on most manufacturers!
THE OUTLET (800) 588-3283

National

American Discount Medical
FOR DISCOUNTS ON ALL YOUR EQUIPMENT NEEDS! Save on Strollers-Convaid, Carre Rover, MacLaren; Scooters; Wheelchairs; Tumbleforms; Walkers; Seating/ Positioning Equip.; and Standers for school or home. Call (800) 877-9100 for FREE BROCHURE.

Consumer Care Products, Inc.
P.O. Box 684
Sheboygan, WI 53082-0684
(414) 459-8353

Access Medical Supply
2006 Crown Plaza Drive
Columbus, OH 43235
(800) 242-2460
Attends Youth Briefs fits children 35-75 lbs. $53.95/cs (96). Free Delivery. Also—Depend, Serenity, other items. Manufacturer's coupons accepted. Free Catalog!

H.D.I.S.
1215 Deiman Industrial Court
Olivette, MO 63132
(800) 538-1036
See our ad in this issue

U.S. Medical Corporation
14575 Manchester Road
Manchester, MO 63011
(800) 40-USMED/
(800) 408-7633
FREE SAMPLE: YOUTH & ADULT BRIEFS. Complete Line of Incontinent Products. Delivered to your home. Call U.S. Medical Corp For All Your Incontinent & Medical Supply Needs.
Low Prices & Free Delivery
MEDICAID ACCEPTED!

YOUTH BRIEF II
FITS 30 TO 70 LBS.
96 FOR $ 39.98
CALL 24HRS.
1-800-777-1111
WOODBURY PRODUCTS INC.
4410 AUSTIN BLVD. ISLAND PARK NY 11558

Youth Incontinence Products
- Overnight Pants with Nylon Exterior
- 24"-44" waist
- Training Pants Toddler-Adult XL
- 2 Piece Brief System Toddler-Adult XL

QUALITY CARE
For Free Brochure
Call: 1-800-259-3099

Med-Sell
10556 Combie Rd. #6219
Auburn, CA 95602
(916) 268-8847
Your published or Internet Resource guide for previously owned medical equipment/housing
http://www.nccn.net/~medsell/

Care Electronics Inc.
5741 Arapahoe Ave. #2A
Boulder, CO 80303
(303) 444-2273
WanderCARE systems notify caregivers when their wanderer leaves home. Locates them up to one mile away. New Low Price. Call for FREE CATALOG.

Hig's Aluminum Products
10625 Maple Lane
Rogers, MN 55374
(612) 498-7304
Ramps, Factory Direct, Light Weight Aluminum, Portable, 2 & 4-Way Folding, Telescoping Tracks, Threshold, Van, Scooter & Approach Ramps
FREE catalog

The Respite Source
A simple, step-by-step Respite Resource Guide on how to find safe, reliable Respite Care help in your own community!
Also available
"How to start a Respite Program" Handbook + Consulting
Only $20
To order: call 1-800-483-4928 or Send check to:
The Respite Source
P.O. Box 160
Louisville, CO 80027
Allow 3-6 weeks for delivery S/H incl.

Van Conversion Dealers

Connecticut

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors, drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Indiana

C & C Ford - Mercury
103 East 5th Street
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors. Braun lifts & tiedowns installed by certified technicians. NMEDA member

Illinois

C & C Ford - Mercury
103 East 5th Street
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors. Braun lifts & tiedowns installed by certified technicians. NMEDA member.

Washable Affordable Tossable
BIBS
Great for traveling & everyday use. One side absorbent, waterproof on the other side. Large pocket for catching food. Can be washed up to 5 times
Package of 5 for $2.50
BAMI (800) 642-4526

Kentucky

C & C Ford - Mercury
103 East 5th Street
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors. Braun lifts & tiedowns installed by certified technicians. NMEDA member.

New Jersey

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/
(800) ARCOLA-1
New-Used-Trade-Lease-Buy
Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Causeway Ford/Lnc/Merc/Jeep/Eagle
375 Rt 72 1 mile East exit 63 GSP
Manahawkin, NJ 08050
(609) 597-8083
New/used van conversion full-mini we stock IMS/Vantage Mini-Vans Dealer for Ricon, EMC, EZLock, Bruno. Financing available NMEDA member.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors, drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member

New York

Arcola Mobility
51 Karo Road
Carlstadt, NJ 07072
(201) 507-8500/
(800) ARCOLA-1
New-Used-Trade-Lease-Buy
Full sized, mini, rear and side entry. We carry products from the following manufacturers: Braun, KneeKar, Vantage, Ricon, and Pick-A-Lift. If we don't have it, we'll find it! Financing is available. NMEDA Member. Please call for more info.

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors, drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member

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Marketplace

Tim's Trim, Inc.
30 Bermar Park
Rochester, NY 14624
(716) 429-6270
Vehicle modifications. Drop floors. Raised tops/Doors. Driving equip. Touch pads. Lifts. NMEDA member. Please call for more information.

Ohio

C & C Ford - Mercury
103 East 5th Street
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors. Braun lifts & tiedowns installed by certified technicians. NMEDA member.

Pennsylvania

Drive-Master, Inc.
9 Spielman Road
Fairfield, NJ 07004
(201) 808-9709
Full service mobility center, raised tops/doors, drop floors, custom driving equipment; distributors for Mobile Tech., Crow River lifts, Ricon, IMS, EZ Lock, and EMC touch pad systems. 41 yrs. of service to the disabled community. Please call for more information. NMEDA member.

Tennessee

C & C Ford - Mercury
103 East 5th Street
Sturgis, KY 42459
(800) 332-6696
New/used van conversions, raised roof & doors. Braun lifts & tiedowns installed by certified technicians. NMEDA member.

BLUE SKY CYCLE CARTS

P.O. Box 5788 • Bend, OR 97708 • (800) 669-1753

- Low profile insures maximum stability
- Comfortable cloth-covered bucket seat
- 5-Point safety harness prevents slipping
- Seats child or adult (4-ft. minimum height)
- Carries up to 200 lb. weight
- Large, easy-rolling 24-inch pneumatic tires

BOOKS, AUDIO/VIDEO & EDUCATIONAL MATERIAL

Free—The NEW Special Needs Project Book Catalog
The best books from all publishers about disabilities. Comprehensive resources for parents, children & professionals. Special Needs Project, 3463 State Street, Santa Barbara, CA 93105, (800) 333-6867.

Free—The 1996 Woodbine House/Special-Needs Collection, a catalog of excellent books for parents, children, and professionals on autism, CP, Down syndrome, Tourette syndrome, mental retardation, visual impairment, physical disabilities, special education, and more. Woodbine House, 6510 Bells Mill Road, Bethesda, MD 20817, (800) 843-7323.

Jason & Nordic Publishers
PO Box 441, Hollidaysburg, PA 16648, Fax (814) 696-4250
Phone (814) 696-2920
Approved by the American Academy of Pediatrics.
Upbeat stories with colorful illustrations address real issues found in the lives of children with disabilities, their families and friends.

HMS School

For Children With Cerebral Palsy

Serving children with multiple disabilities resulting from cerebral palsy or traumatic brain injury who need comprehensive, individually structured programs that include:

- ***Physical Therapy***
- ***Occupational Therapy***
- ***Speech and Language Therapy***
- ***Communication Aids***
- ***Special Education***
- ***Music Therapy***
- ***Special Medical Attention***
- ***Adapted Recreational Activities***

HMS, open to students two to 21 years, offers all of these services and more. The experienced staff and well-respected consultants provide strong interdisciplinary programs for day and residential students at the licensed private school.

For more information write or call:
Diane L. Gallagher, Director
HMS School for Children with Cerebral Palsy
4400 Baltimore Avenue, Philadelphia, PA 19104
(215)222-2566

Circle #200

Superior Quality
Community Living Opportunities

For more than 65 years, Martha Lloyd Community Services has provided superior quality day and residential programs for adults with mental retardation. Located in the scenic rural village of Troy, Pennsylvania, Martha Lloyd has a unique relationship with its neighbors. Residents are valued members of the community and make full use of its resources.

There are five programs for women (from semi-independent to highly structured) including one specifically designed for mature women. **A new community-based program for men is now available.**

- Life skills and vocational training
- Employment opportunities at Martha Lloyd and in the Troy community
- Easy access to nearby community resources including retail shops, restaurants, churches, and recreation
- A caring professional staff experienced in working with developmental disabilities
- Our interdisciplinary team approach assures continuity and consistency in individual planning
- Unique leisure and recreational experiences in a rural community setting
- Excellent health care provided by on-staff health professionals and a community medical center
- Annual fees among the lowest in the nation

MARTHA LLOYD COMMUNITY SERVICES

For Information Call
(717) 297-2185
or write: Martha Lloyd Community Services, 190 West Main St., Troy, PA 16947

Circle #157

SCHOOL DIRECTORY

Arkansas

Millcreek School of Arkansas
Residential ICF/MR
Hwy 79 PO Box 727
Fordyce, AR 71742
(501) 352-8203
Fax (501) 352-5311
Est. for K-12, dually diagnosed students in a treatment setting located in beautiful south Ark.

California

Blind Children's Learning Center
18542-B Vanderlip Avenue
Santa Ana, CA 92705
(714) 573-8888
Fax (714) 573-4944

Kaplan Foundation
7150 Santa Juanita Avenue
Orangevale, CA 95662
(916) 988-0258
Fax (916) 988-0423
Residential & educational program for Autistic & PDD (ages 3-17) consulting available contact: Karen Fitzgerald

The National Center on Deafness
California State University-Northridge
18111 Nordhoff Street
Northridge, CA 91330
(818) 885-2614
Fax (818) 885-4899

Colorado

Colorado School for the Deaf and the Blind
33 N Institute Street
Colorado Springs, CO 80903
(719) 578-2102
Fax (719) 578-2239

Connecticut

The Connecticut Institute for the Blind
120 Holcomb Street
Hartford, CT 06112-1589
(860) 242-2274
Fax (860) 242-3103
Learning for Oak Hill School students takes place every day, everywhere. Our community-based residential and educational programs provide students with continuity of learning, a sense of pride and accomplishment in being a part of their community and on-going support to reach their highest potential.

Florida

Ralph J. Baudhuin School of Nova
Southeastern University
3301 College Avenue
Ft. Lauderdale, FL 33314
(954) 475-7324
Fax (954) 476-4843
Learning disabled Attention Deficit and Communication Disorders.IEPs. Low student-teacher ratio, computer lab media center, mainstream opportunities, parent counseling and support groups, speech and language therapy, nurse, guidance program.

Hope Center
666 SW 4th Street
Miami, FL 33130
(305) 545-7572
Fax (305) 325-0382
Residential and day training for all levels of developmentally disabled individuals. No upper age limit. Training includes survival and vocational education and supported employment. Residential programs include dormitories and community living. Sliding scale.

MacDonald Training Center, Inc.
4304 Boy Scout Boulevard
Tampa, FL 33607
(813) 870-1300
Fax (813) 872-6010

Georgia

Agape Village
3711 Agape Village Road
Macon, GA 31210
(912) 471-3700
Providing mentally disabled with 50 acre protected place to live, work in greenhouse and enjoy active life with supervision.

Illinois

Keshet
3210 Dundee Road
Northbrook, IL 60062
(847) 205-0274
Fax (847) 205-1530

Kansas

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(800) 835-1043
Fax (316) 262-0170
Heartspring serves children ages 5 to 21 with multiple disabilities. Assessments, outpatient therapies & hearing services are also available.
SEE OUR AD ON PAGE 6

Kentucky

Stewart Home School
4200 Lawrenceburg Road
Frankfort, KY 40601
(502) 227-4821
Fax (502) 227-3013
SEE OUR AD ON PAGE 77

Maine

Bancroft
Lighthouse Road
Owl's Head, ME 04854
(207) 594-7261
Fax (207) 596-7662
Programs for people with developmental disabilities/brain injuries. See Bancroft in New Jersey section.
SEE OUR AD ON PAGE 80

Massachusetts

Amego
10 Merrymount Road/
Quincy, MA 02169
(617) 471-2345
Fax (617) 770-1201
Vocational, educational and residential programs for children, adolescents and adults with Autism and related disorders.

Berkshire Meadows
249 N Plain Road
Housatonic, MA 02136
(413) 528-2523
Fax (413) 528-0293
For children and adults who have severe neurodevelopmental disabilities and complex medical problems. Private, non-profit residential setting in the Berkshires, offering a comprehensive approach to each individual's well being with integrated educational, medical and rehabilitative services.
SEE OUR AD ON PAGE 13

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702-0372
(508) 644-3101
Fax (508) 644-3101 ext 372
SEE OUR AD ON PAGE 73

Cotting School
453 Concord Avenue
Lexington, MA 02173
(617) 862-7323
Cotting School welcomes boys & girls ages 3-22 with physical, medical, learning & communication disabilities. We offer individualized academic, pre-vocational and social experiences to build confidence & enhance students' self esteem.
SEE OUR AD ON PAGE 86

Evergreen Center
345 Fortune Boulevard
Milford, MA 01757
(508) 473-3882
Fax (508) 634-3251
SEE OUR AD ON PAGE 91

Kennedy Day School
30 Warren Street
Boston, MA 02135-3680
(617) 254-3800
Fax (617) 254-6842

Language and Cognitive Development Center
11 Wyman Street/PO Box 270
Boston (JP), MA 02130
(800) 218-5232
Fax (617) 522-9631

League School of Boston
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260
Fax (617) 964-3264
SEE OUR AD ON PAGE 89

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015
Day/residential school for children with develop. Disabilities, behavior disorders age 3-22. Integrated preschool, inclusion services, staff intensive program, functional activity based curriculum, supported employment in modern school and group homes.

New England Villages, Inc.
664 School Street
Pembroke, MA 02359
(617) 293-5461
Fax (617) 294-8385
Exceptional private community for MR adults offering a range of residential options, vocational, recreation and social opportunities.
SEE OUR AD ON PAGE 38

Protestant Guild Learning Center
411 Waverly Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/ residential.

St. Colletta's of Massachusetts Cardinal Cushing School and Training Center
400 Washington Street
Hanover, MA 02339
(617) 826-6371
Fax (617) 826-6474
Day/residential school, mild to severe developmental disabilities age 6-22, functional academics, life/social/community/vocational training.
SEE OUR AD ON PAGE 58

Mississippi

The Baddour Center
Highway 51 South
Senatobia, MS 38668
(601) 562-9666 ext 225
Fax (601) 562-6979

Nebraska

Meyer Rehabilitation Institute
University of Nebraska
Medical Center
600 S. 42nd St. / PO Box 985450
Omaha, NE 68198-5450
(800) 656-3937
Fax (402) 559-5737

New Hampshire

Cedarcrest
91 Maple Avenue
Keene, NH 03431
(603) 358-3384
Fax (603) 358-6485
Small, unique children's home and school serving infants to teens who are medically fragile or multiply disabled; personalized care.

SCHOOL DIRECTORY

New Hampshire

Crotched Mountain
Rehabilitation Center, Inc.
1 Verney Drive
Greenfield, NH 03047
(603) 547-3311, ext. 235
A comprehensive preparatory school and rehabilitation center providing the best in education, a guided return to the community, access to community housing, education and support services for lifelong planning.
SEE OUR AD ON PAGE 43

The Lukas Community
PO Box 137
Temple, NH 03084
(603) 878-4796
Fax (603) 878-4796
SEE OUR AD ON PAGE 59

New Jersey

Bancroft
Hopkins Lane, PO Box 20
Haddonfield, NJ 08033-0018
(609) 429-0010 ext. 347
Fax (609) 429-4755
State-of-the-art programs in NJ and Maine for children, adults with developmental disabilities/ brain injuries. Full continuum of educational, vocational and living options. Behavioral intervention and outpatient services available.
SEE OUR AD ON PAGE 80

Matheny School and Hospital
Peapack, NJ 07977
(908) 234-0011
Fax (908) 719-2137
*For 50 years, an habilitation center for young people with severe physical disabilities.
*Academic & life-skills on a residential & outpatient basis.

New York

Ferncliff Manor Residential School
1154 Saw Mill River Road
Yonkers, NY 10710
(914) 968-4854
Fax (914) 968-4857

Lake Grove Schools
PO Box 1306
Lake Grove, NY 11755-1306
(516) 585-8779
Fax (516) 688-9215

Pathfinder Village
for Down Syndrome
Edmeston, NY 13335
(607) 965-8377
Fax (607) 965-8655
SEE OUR AD ON PAGE 82

To place an ad, contact:
ROY WHITAKER
(505) 821-3414
or fax to: (505) 821-2178

Upstate Home for Children Inc.
RR1 Box 155, Route 28
Oneonta, NY 13820-9753
(607) 286-7171
Fax (607) 286-7277
Main campus residential school student centered education based on a child's strengths and interests. Clinic supports and assistive technology provided in natural settings. Call for an information packet Kathy Yager-Krol, School Director.

YAI/New York League for Early Learning
Administrative Office
460 W. 34th Street
New York, NY 10001
Dr. Ronald S. Lenkowsky, Director
(212) 563-7474, ext 213
Fax (212) 268-1083

YAI/New York League for Early Learning
William O'Connor School
420 95th Street
Brooklyn, NY 11209
Bernadette Flynn, Coordinator
(718) 680-9751
Fax (718) 680-7977

YAI/New York League for Early Learning
Office Home-Based Services
3 East 19th Street
New York, NY 10003
Patricia Donini, Coordinator
(212) 420-0510
Fax (212) 677-5241

YAI/New York League for Early Learning
Gramercy School
3 East 19th Street
New York, NY 10003
Patricia Harmon, Coordinator
(212) 420-0510
Fax (212) 420-0563

YAI/New York League for Early Learning
Harry H. Gordon School
2465 Bathgate Avenue
Bronx, NY 10458
Ann Esposito, Coordinator
(718) 367-5917
Fax (718) 367-6692

Pennsylvania

Camphill Special School
1784 Fairview Road
Glenmore, PA 19343
(610) 469-9236
Fax (610)469-9758
Children's Village, DD, Residential/day programs, extensive therapies. Waldorf-based curriculum, focus on arts/festivals. School year/ summer camp, pool, equestrian therapy. Students share homes with curative educators & staff children. On-campus medical staff & facility. IMAGINE THE BEST!

The National Association of Private Schools for Exceptional Children

Founded in 1971, NAPSEC is dedicated to promoting excellence in private special educational settings for exceptional children.

- ***Nationwide Membership:*** Represents over 200 schools nationally, and over 600 at the state level through its Council of Affiliated State Associations, that provide special education to both privately and publicly placed children.
- ***Free Referral Service:*** Offered to parents and professionals who are looking for an appropriate private special education placement for their child or client.
- ***National Representation:*** Advocates for the rights of exceptional children and their families.

For referral or membership information please contact:

NAPSEC

1522 K Street, NW, Suite 1032
Washington, DC 20005
(202) 408-3338 • (202) 408-3340 facsimile
Sherry L. Kolbe, Executive Director

Circle #118

BEST COPY AVAILABLE

Pennsylvania

The Devereux Foundation
(800) 345-1292 Ext. 3045
(610) 964-3045
Fax (610) 971-4600
Residential, day and community-based treatment programs nationwide. Comprehensive services to individuals of all ages who have emotional disorders, developmental disabilities, mental retardation, dual diagnoses (ed/mr), and autism.
SEE OUR AD ON PAGE 36

HMS School for Children with CP
4400 Baltimore Avenue
Philadelphia, PA 19104
(215) 222-2566
Fax (215) 222-1889
For students with severe disabilities from Cerebral Palsy or brain injury; integrated intensive therapies, assistive technologies.
SEE OUR AD ON PAGE 94

Keystone City Residence
406 N. Washington Avenue
Scranton, PA 18503
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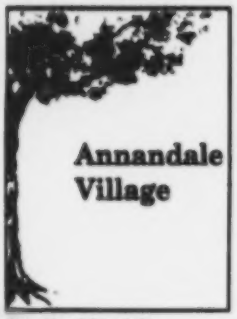

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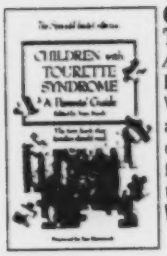

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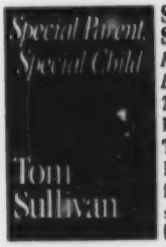

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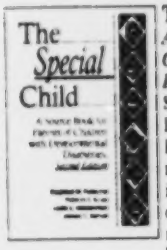

THE SPECIAL CHILD
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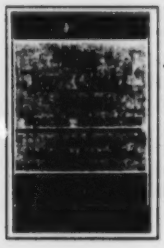

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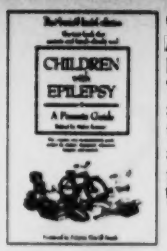

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My Cousin Samantha

Lindsay, 8, proudly holds two-month-old Samantha shortly after her release from the hospital in 1993.

Fresh from the beauty salon after Sammi's second haircut, Samantha and Lindsay strike a pose.

Samantha Bosch is my baby cousin. She is 16 months old. She was supposed to be born on Christmas, but she was three months premature. She was the tiniest little thing. We only got to see her one time in the hospital. We had to wear special little robes. She was hooked up to a respirator and a lot of other machines. She was so small she could wear preemie Cabbage Patch clothes. She had to stay in the hospital for two months so she could grow. Finally she came home.

Last year we started taking care of Sammi because her mom—my aunt—had to go back to work. Sammi is doing much better now. Four therapists come to our house. Sammi is getting better at holding things. Whenever she cries, you can sing "The Itsy Bitsy Spider" and she will stop crying; she loves that song. Sammi and I always play together. I love her. **EP**

Lindsay Bosch, 9, lives in Shoreham, New York with her parents and siblings, Erin, 12, and Gerard, 17. She attends the Miller Avenue School in Shoreham, where she is in the fourth grade. She enjoys reading, gymnastics and art.

Lindsay's mom, Teresa, takes care of Samantha while Samantha's mom, Ellen, works. "Even though Lindsay and Samantha are not siblings, they are very close," writes Ellen. Samantha, now 2, was born three months premature, and had a grade IV intraventricular hemorrhage, which caused cerebral palsy and hydrocephalus.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005

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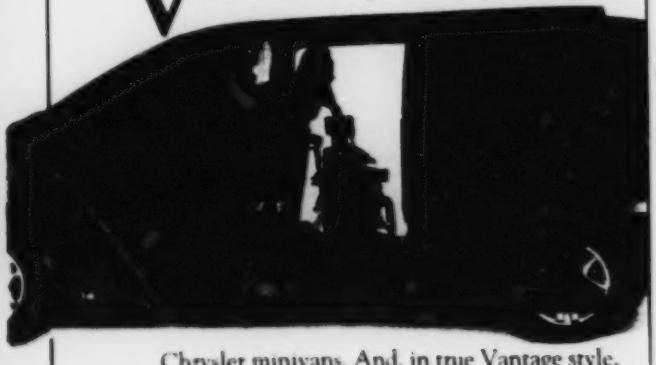

Chrysler minivans. And, in true Vantage style, we've given them a whole new angle...literally!

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[2] Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance Plan. Vehicles covered by the Lincoln Commitment, Mercury Commitment or Red Carpet Lease plans may have additional benefits.

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PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

APRIL 1998 VOL. 28, ISSUE 4

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Cover: The Campbell kids, (from left) Mary Catherine, 5, Jimmy, 15 months, and Caroline, 3, enjoy the warm summer breeze among the sand dunes in Ocean Isle, North Carolina. The Campbells spend one week every summer at Ocean Isle, in a beach house filled to the brim with extended family—parents Rich and Claire, assorted cousins, aunts and uncles.

With 18 people in the house—eight of them young children—this family vacation is far from relaxing; but Jimmy, who has mosaic Down syndrome, revels in the excitement and the activity. "Sandbox play is one of his favorite year-round activities," says Claire, "and the sand dunes of Ocean Isle provide him with what feels like the world's biggest sandbox." When not enjoying the sunshine of the Carolina coast, the Campbells live in Oxford, Pennsylvania. Photo: Rich Campbell.

BPA

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EDITOR'S DESK

Vacation and Travel

Today, children and young adults with disabilities and their families can vacation together, enjoy comfortable accommodations, and travel by various methods. In this issue, we focus on air travel. Traditionally, individuals with disabilities have had difficulties traveling by air. Now, a little bit of advance planning can bring an enjoyable, relatively worry-free vacation. Contact airlines, hotels and theme parks well ahead of time to make proper preparations and anticipate potential barriers. Planning ahead and providing advance notice of special needs can make family vacationing (with or without children) comfortable and fun.

STANLEY D. KLEIN, PH.D.

When I first read Barbara Boelter's article, I was surprised to learn that people who are deaf are having difficulties enjoying their visits to Disney World. We are glad to present a response from Disney World which explains the changes they are making to better accommodate deaf visitors.

New relationships

Last fall, we made contact with two fine groups—the National Family Caregivers Association and the Mothers from Hell. We are very pleased to present some material from their perspectives. And, we couldn't resist inviting our Role Model from October 1995, Frank Bernard, Jr., to help us illustrate the humorous suggestions from the Mothers from Hell. We have decided to include "Funny as a Crutch," a comic strip created by Frank, in each issue. Look for it in this month's What's Happening. These lighthearted approaches to complicated day-to-day issues also send serious messages to parents, children and professionals.

We are also launching Technology, a regular question-and-answer department prepared in collaboration with the dedicated team at the Communication Enhancement Center of Children's Hospital in Boston.

25th anniversary celebration

EXCEPTIONAL PARENT's twenty-fifth anniversary celebration is now planned for mid-October at Disney Land in Anaheim, California. Our decision to move was determined by the availability of accommodations. Stay tuned!

Going on-line

We are pleased to announce that EXCEPTIONAL PARENT, in partnership with the Boston-based Family Education Network (FEN), will build a special needs site on the Internet, at http://families.com. The site will provide a wide range of information of interest to both parents, children and professionals. FEN will be a central source of information, relevant programming, and useful services to help parents manage their everyday lives, get involved in their communities and prepare their children for the future. "Preview" services will be up and running on April 23; the full release version will debut in September. We will be describing this exciting collaboration in future issues.

Help wanted

We invite readers who are experienced freelance writers or photographers to send their resumés and references to our Brookline office.

News flash

Catherine LaFond-Evans of Warrensburg, NY, has informed us that a New York state Supreme Court justice has ruled that the family's private health insurance should pay for the life-sustaining formula needed by LaFond-Evans' three children. In May, we will cover this important story in detail (see Letters, this issue).

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For subscription and advertising information, see page 58

BPA

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Circle #110

LETTERS

Fighting for Haley's Life

Thank you so much for the wonderful job you did with my story about our family's fight to obtain insurance coverage for our daughter's life-sustaining formula ("Fighting for Haley's Life," February 1996). Seeing my words in print has made an indelible mark on my heart. Many publications backed from our saga, fearing the repercussions of taking on a behemoth of an insurance company such as Blue Cross. But you were true to your word and stood with us against all odds.

This has never been an easy battle. Getting anyone to listen has taken a lot of time, work, energy and courage. Having been rejected, turned down and blatantly told that we are just too controversial, I am all the more appreciative of what you have done to help not only us, but the many other families with similar needs. Thank you for being so honest in your coverage of life's truths, especially those truths that are obscure and unpopular in the eyes of many. For now, our family has the help we need, but there is so much more work to be done.

We need you and your fabulous publication more every day. Because of EXCEPTIONAL PARENT, I don't feel quite as alone as I did before. Knowing that you care so deeply about your readers gives me both hope and strength—sentiments I need after experiencing so much negativity and failure. I am certain other readers feel the same way.

I have received calls and letters from many people since my article was printed. Some have used our example as ammunition to fight their own insurance companies—sometimes Blue Cross, sometimes other companies. Some families have won their fights already. Blue Cross does not want people to know that they are covering formulas for some people. They do not want more of the negative publicity generated by cases like ours, so they are quietly responding to these requests by granting coverage.

Thank you again for caring enough to get involved and take a stand. I am still working to enact legislative changes that would mandate insurance coverage of formulas, and your publication has helped tremendously in that battle. I am happy to hear from other readers.

Judy Engleman
284 Jonquil Place
Pittsburgh, PA 15228

Change of Heart

One year ago, I wrote EXCEPTIONAL PARENT a grumpy letter about my stepdaughter, Susan, moving into her own apartment. I was grumpy because I was sure she was making a mistake.

Yesterday, Susan moved into a bigger apartment, in a nicer neighborhood, with a roommate. She was not happy with her first apartment, so with the help of the staff at our local independent living center, she apartment-shopped, then found a roommate when she realized it was the only way she could afford a nicer place.

In the last year, Susan has become so much more independent. She now does her own laundry with help, keeps her apartment clean and goes out for recreation on her own without waiting for one of her relatives to take her. She has also weathered many "exciting" experiences with grace—being present at a bank robbery, having her purse stolen, dealing with good and bad dating relationships.

I am so proud of Susan. It's true, she will always need some help, but then again, *everyone* needs some help from time to time.

C.U., Ohio

continued on page 6

EXCEPTIONAL PARENT
The Magazine for Families and Professionals
Providing Your Child or Young Adult With a Disability

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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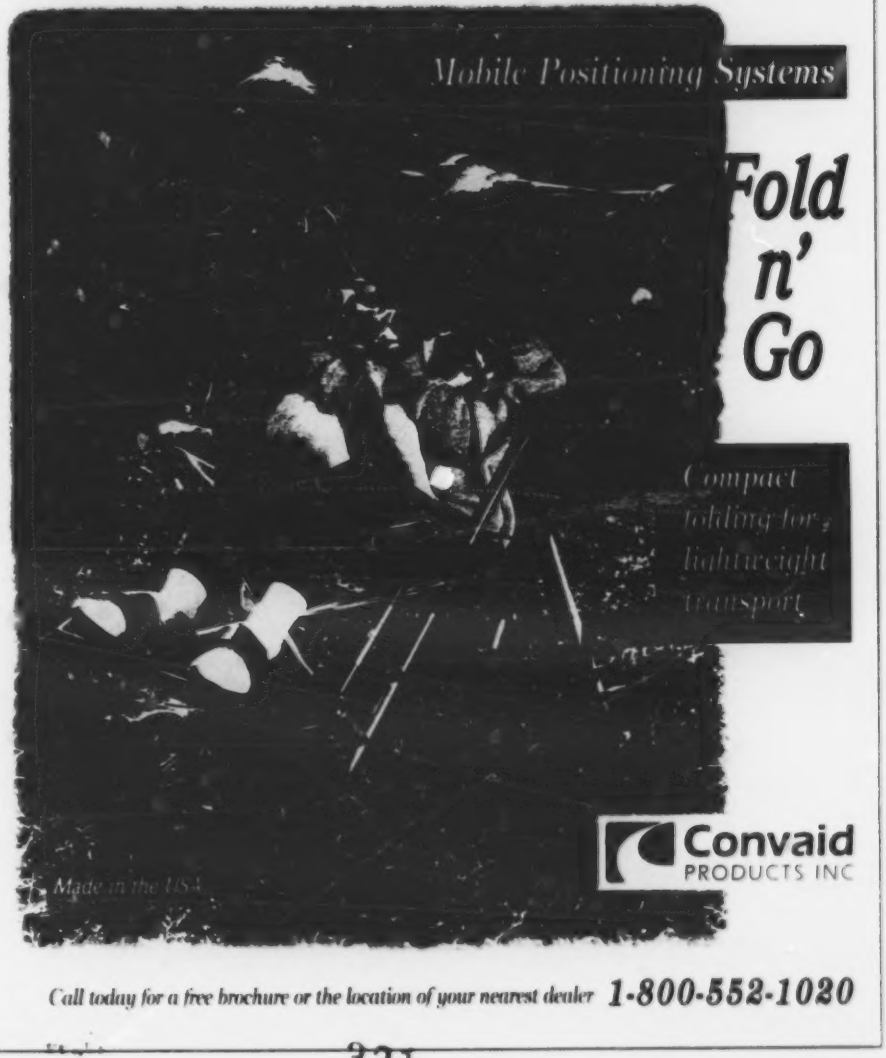

Call today for a free brochure or the location of your nearest dealer **1-800-552-1020**

Circle #64

continued from page 4

Resource Guide

I want you to know how valuable your annual Resource Guides have been to the FSHD (facio-scapulo-humeral dystrophy) community. FSHD is relatively rare, and diagnosis is difficult. Our organization is specifically dedicated to information, education, research and networking for individuals concerned with this condition. Your Resource Guide has led many parents and family members who are living with this disorder to our organization (FSH Society, 3 Westwood Rd., Lexington, MA 02173; 617/860-0501). I get calls from parents who say, "I read about you in EXCEPTIONAL PARENT. I have never met or spoken to anyone else with FSHD..."

Carol A. Perez, Executive Director
FSH Society
Lexington, Massachusetts

Thanks!

I have been a nurse with Children's Rehabilitation Services in the Alabama Department of Rehabilitation Services for more than 21 years. I discovered EXCEPTIONAL PARENT about 15 years ago and have learned a lot from reading it. From *Search*, I've come to understand more about unusual disorders; from *Respond*, I've learned about parents' creativity and willingness to share and help others. Most of all, I have learned that when families find each other, it is the end of isolation and the beginning of better days.

I recommend the magazine to the new families I encounter, and encourage other families to read it or to write a *Search* letter about a problem they may have. I keep subscription cards where families can find them. Most of all, I recommend that new staff members hired at Children's Rehabilitation Services read a few back issues and each issue thereafter.

I cannot tell the parents I work with that I know exactly how they feel, but I can tell them that other parents have discussed similar issues with me and that I recently read an article or letter in EXCEPTIONAL PARENT about that very subject—"let me find it so you can read it!"

Madalyn Rochford, R.N.
Children's Rehabilitation Services
Jackson, Alabama

Tell us about...

... your positive interactions with doctors.

***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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332

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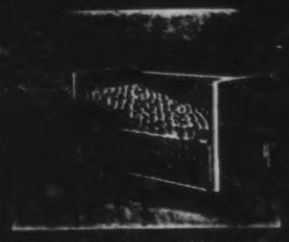

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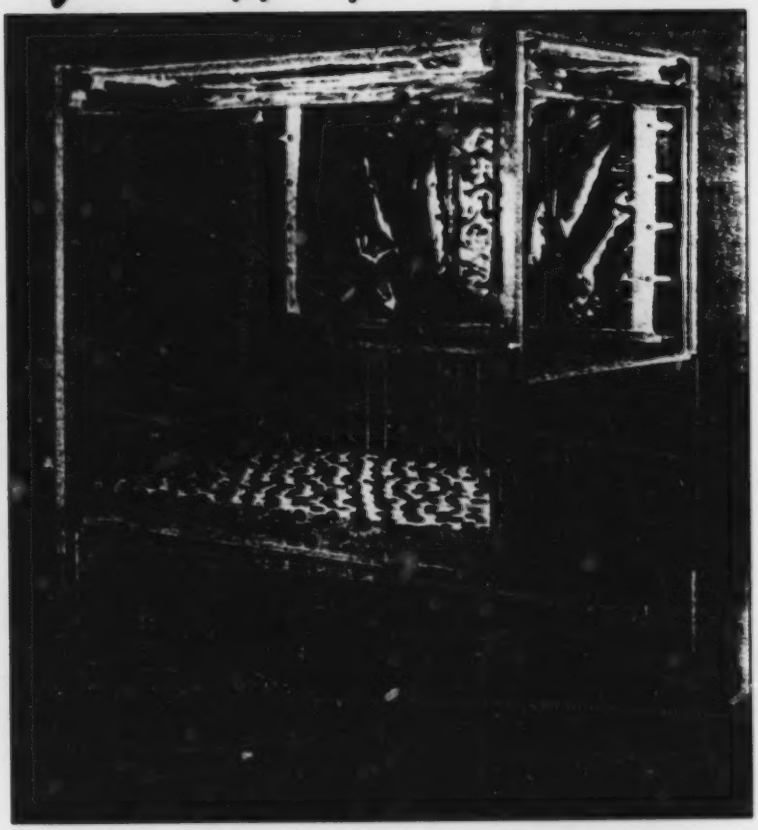

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...it is must reading for all those with a handicapped child.

Ann Landers

...highly recommend... all parents of children with disabilities.

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is the magazine for parents and professionals involved in the care and development of children and young adults with special needs including:

Physical Disabilities
Developmental Disabilities
Mental Retardation
Autism, Epilepsy
Learning Disabilities
Perceptual Disabilities
Hearing Impairments
Vision Impairments
Emotional Problems
Chronic Illnesses.

EXCEPTIONAL PARENT'S mission is to

PROVIDE practical guidance and support for parents, educators and professionals caring for children and young adults with disabilities and special health care needs.

INFORM parents and professionals about current and changing rights, laws and programs for children and young adults with disabilities and their families.

SERVE as a network, a forum for the exchange of ideas, experience and advice between parents, professionals and educators.

FOCUS on the child first, the disability second.

read it monthly.

If the subscription card is missing, please call 800-247-8080

SEARCH

Nemaline Myopathy

My grandson is 10 months old and lives with us. At about two months of age, he was diagnosed with nemaline myopathy (also known as congenital rod disease or rod myopathy), a congenital disease of the skeletal muscles.

He has a g-tube and was doing pretty well all summer, but then he was taken to the hospital with respiratory distress in October. He now has a tracheostomy and is on a bi-pap machine to aid his breathing.

I understand this is a rare disease, so I do not have much idea about what to expect in the future. He is still pretty weak; he canhot hold his head up for long, nor does he move his legs much. I need to know what could help in terms of therapy and stimulation. The doctors are not much help; they seem very pessimistic.

I would like to hear from others who have children with this condition. He is the sweetest baby—so alert and bright. I ache to help him, but I don't know how.

D.H., Ohio

Placing an Adult Child

My husband and I have a 14-year-old son who has severe mental retardation, along with other disabilities. Noah is a wonderful, happy child but increasingly difficult to care for. We know the time will come when he will no longer be able to live at home because as we become older, we will not be able to attend to his physical needs.

We would like to hear from other parents who have "placed" their adult children in group homes or other facilities. How soon should we begin making arrangements for Noah's transition from home to another living arrangement? How can families find out about various options? I imagine some states and communities offer better facilities than others. How does one find out about what's available in other places? My husband and I would be more than willing to relocate to an area that has better options for Noah.

B.F., Virginia

Fetal Alcohol Syndrome

I am the adoptive parent of a three-year-old child with several diagnoses. Casey has lived with me as a foster child since his birth. I was able to complete his adoption in September 1994.

Casey was born full-term, weighing four pounds, to an alcoholic mother, who also may have used drugs. He received an initial diagnosis of intrauterine growth retardation and possible fetal alcohol syndrome (FAS). He was given oxygen for approximately one week after birth. He had seizures and feeding difficulties. He was very fussy and had a high-pitched cry (he continues to have a high-pitched squeal). For several months, Casey had problems with bradycardia (slower-than-normal heartbeat) and apnea (periods when he would stop breathing).

At three months of age, doctors questioned his vision and hearing abilities. They said he would probably not be able to walk, talk or do much of anything else. To our wonderful surprise, he now does all of the above and much more!

Casey's diagnoses include developmental delay, muscle weakness, complex partial seizure disorder, visual impairment related to optic nerve hypoplasia, asthma, attention deficit hyperactivity disorder (ADHD) and possible Russell-Silver syndrome (a form of dwarfism). He is fed through a g-tube and receives physical and occupational therapy. Casey exhibits many symptoms associated with FAS, including

continued on page 12

For more information on Apple products, contact us at 800-600-7808 or 800-755-0601 (TTY).

Apple

If you could give your child anything in the world, what would it be?

the Gift of

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For a child with multiple disabilities, peaceful behavior can open many doors ... to more rewarding relationships with family ... to their own feelings ... even to new friendships. Unfortunately, aggressive behaviors are sometimes the only way they have to reach out.

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Circle #155

SEARCH

continued from page 11

unique facial features. He is still very small, weighing only 23 pounds. He has been hospitalized several times due to the asthma. He has had tubes in both ears due to infections, surgery for reflux, and may face surgery to remove his tonsils and adenoids. He seems to catch a virus every time the wind blows.

Casey takes all of this in stride and has become a happy and affectionate little boy. I would like to hear from other parents of children with FAS or problems similar to Casey's. We are trying to make decisions about preschool programs and would welcome any suggestions.

L.M., Georgia

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax:
Search or Respond
Exceptional Parent
209 Harvard St., Ste. 303
Brookline, MA 02146-5005
Fax: (617) 730-8742

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518. Also, see "National Resources for Specific Disabilities and Conditions" in *Exceptional Parent's 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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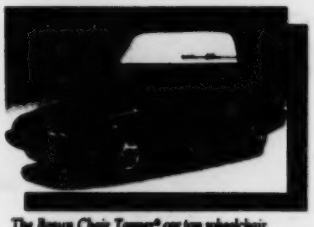
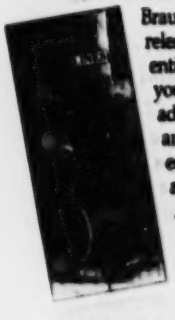


The Braun Chair Topper® car top wheelchair carrier is available in the driver's side configuration of the optional passenger side design.



Braun has recently released a helpful booklet entitled "Guidelines". If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All sources for motor vehicle rebates are also listed in this comprehensive booklet.

"Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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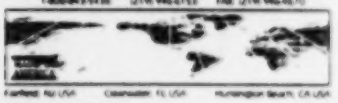

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Circle #210

RESPOND

Calling 9-1-1?

B.L. (November 1995) worried that, in the event of an emergency, her eight-year-old son, who has severe difficulties with speech, would not be able to communicate with a 9-1-1 operator. He can dial a telephone, but B.L. fears that he would not be able to provide any relevant information. She was looking for helpful solutions to this problem.

My 12-year-old son has multiple disabilities. He is very vocal and loves to "talk" on the phone though he has little actual speech. I, too, wondered what would happen if there was an emergency at our home and he was the only one able to call for help. His favorite TV program is "Rescue 9-1-1," so he knows the correct number to call, but I knew he would never be able to make himself understood.

I explained my son's situation to our local police department. They entered all the information about my "chatterbox" in their computer and told me that if a 9-1-1 call came from our home, they would respond immediately, regardless of what was or wasn't said on our end of the phone.

One day, my son managed to get to the phone and call 9-1-1. As soon as he heard the operator's voice, he hung up. When the information about my son came up on her computer screen, the operator dispatched an officer to our house and called back to find out if everything was okay. Needless to say, my son got in trouble for using the phone, but I was thrilled to find out that 9-1-1 works!

T.B.S., Texas

■ I am a parent, a firefighter and a paramedic, so I know a few things about emergency services. There are two types of 9-1-1 service: enhanced and non-enhanced. When a 9-1-1 call is made in a community with enhanced service, the name, address, and phone number of the location from where the call originates is automatically displayed on the dispatcher's computer screen. The phone doesn't even have to ring—the information appears as soon as the last "1" is dialed. If no one responds when the dispatcher answers the call, a police officer is sent to investigate.

Contact your local fire department dispatcher. Special needs or other information can be attached to a particular address in the computer. If that address should ever come up—regardless of whether it came in as an interrupted or unanswered call—the dispatcher would have a clue to an emergency. This is a very common practice in our community, especially with families who have children that suffer from apnea (periodic pauses in breathing).

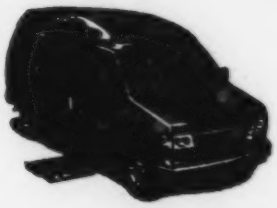
If you use daycare, or your child stays at another address on a regular basis, you can notify the dispatcher of this, too. That way, if a 9-1-1 call comes in from the daycare address during the hours that your child attends, the dispatcher will have your son's special information. This

continued on page 16

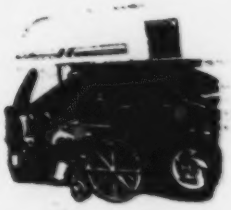
B R A U N

Caravan Entervan® - newly redesigned for '96 and featuring Chrysler's driver-side sliding door.

Lift-A-Way® Lift - the original design that has provided dependable mobility for over 30 years.

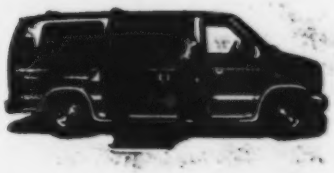


Swing-A-Way® Lift - this innovative design offers the widest clear-path access to the side door in the industry.

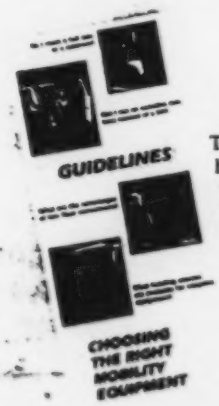


Chair Topper® Wheelchair Carrier - conveniently stores a conventional wheelchair for those who transfer, adding only 22" in height.

Windstar Entervan® - an economical rear-entry solution for those who will have an attendant.



Lift-A-Way® D/C Lift - the latest in Braun's line of personal lifts featuring the ARS (Automatic Roll Stop).



To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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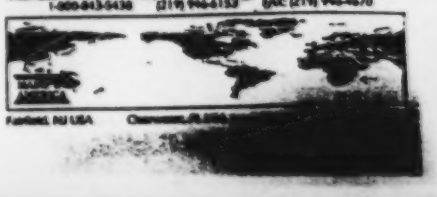

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continued from page 14

"pre-incident planning" eases the fears of parents and better prepares the dispatcher for dealing with your specific situation.

Another suggestion, something I chose for my family a few years ago, is to install a home security system with three panic buttons: police, fire and medical. Some of these services can be expensive, especially if a commercial company installs and monitors the system. I purchased the alarm system directly from a supply company for $310 and installed it myself. I also bought an auto-dialer from a local consumer electronics store for $100; you can get a better product today for about the same price. When triggered (either manually or by the alarm system), the device automatically dials three programmed phone numbers of your choice and delivers a pre-recorded statement three or four times before proceeding to the next number. I programmed ours to dial the fire dispatcher, a family member and the fire dispatcher again.

B.N., Ohio

Caring For an Adult Sibling

K.W. (December 1995) has a 54-year-old sister, Helen Marie, who has mental retardation. Helen Marie now lives with her mother in Chicago, but will come to live with K.W. and her husband in Atlanta when their mother dies. K.W. was looking for suggestions and hints on making Helen Marie's transition a smooth one.

I think it's terrific that you are preparing now for your sister's future transition from Chicago to Atlanta. I hope the following ideas are helpful.

If possible, have Helen Marie visit you in Atlanta for a vacation. This would give her an opportunity to see and experience the new city without pressure. It'll be more difficult for her to get used to her new environment when both of you are grieving the loss of your mother.

Perhaps during Helen Marie's visit, she could participate in some neighborhood activities—some with other folks with disabilities, and some without. Local agencies would help you find out what's going on. While participating, your sister might meet people who would be interested in corresponding with her after she returns to Chicago.

You could also take Helen Marie on a tour of the local rehabilitation center and introduce her to the center's staff. Have the center send its newsletter to her in Chicago. This would ensure that, when the time comes for placement, the center and its staff will be familiar to and with her.

H.A., Pennsylvania

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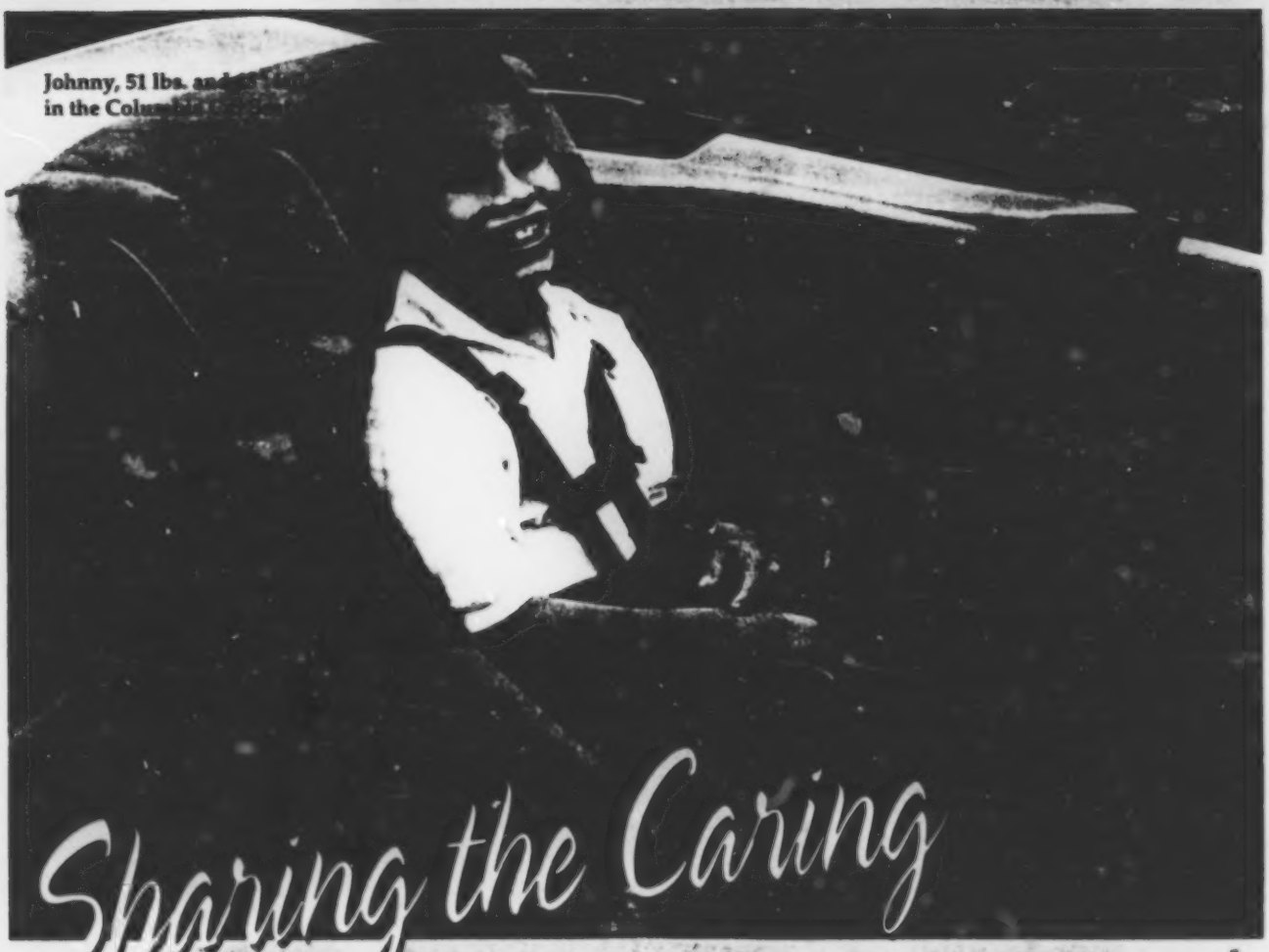

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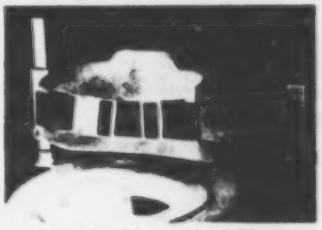

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TRAVEL

Head Out on the Highway

A father and son share the joy of motorcycling

by Don Cecconi

Don and Neal Cecconi took longer and longer trips as they got used to their brand new Honda Gold Wing in 1991. "I had tended to think of Neal as being real fragile as a kid with disabilities," says Don, "but I found he could last longer than me on these rides. He just plunks right in there."

My son, Neal, was born in 1977 with Klippel-Feil syndrome, a rare, congenital disorder. His spine is fused, so he can't move his head or back. He doesn't have enough balance to walk without leg braces, a walker or a guiding hand. He's missing a kidney and has spina bifida. His cognitive skills are like those of a seven-year-old, but he communicates at about the level of a three-year-old. Doctors, and other people who know about such things, tell us Neal's disabilities are profound.

But Neal's disabilities are not the only thing that distinguishes him from most other teenagers. Neal has also traveled nearly 37,000 miles on the back of a motorcycle. As Neal's dad, I'm as amazed by this as anyone.

I've always loved motorcycling. When Neal was young, I took trips alone for my own pleasure. On my Suzuki, the mountain roads of southern California were transformed into my own personal roller coaster. My remarkably patient wife, Gail, who never caught the motorcycle "bug," stayed home to entertain Neal.

But as he grew older, Neal somehow went from being "Momma's boy" to being Dad's best buddy. I found myself spending more and more time with my son, and less and less time on my bike. Neal and I enjoyed many activities together—Boy Scouts, baseball, sailing, swimming, bowling, movies and television. Eventually, I gave up riding completely and sold my beloved motorcycle.

Back in the saddle

One day, after Challenger Little League try-outs, Neal and I found ourselves with some time to kill while Gail stayed at the ball park for some of that committee work moms always end up doing. We went for a walk and ended up at the local Honda motorcycle dealership. We ventured inside and I climbed up on a big Gold Wing touring bike, reminiscing with the dealer about my long-gone motorcycle days. After listening to us for awhile, and probably getting a little bored, Neal asked to get up on the bike with me, so I boosted him up into the saddle. When it was time to leave, he was reluctant to get down.

That night I told Gail about our visit to the Honda showroom. Expecting some kind of maternal reprimand, I was more than a little surprised when she suggested I call the dealer and arrange to take Neal on a test ride.

I had never even considered putting Neal on the back of a motorcycle—for one thing, I didn't think he could do it; and even if he could, I wasn't sure he would like it. But as Gail and I discussed it further, I suddenly found myself selling the idea very hard. I told her about the big passenger seat and floorboards on the Gold Wing touring bike; I even suggested installing armrests and a special backrest for more security. The more I talked about the possibilities, the more enthusiastic I became. What if Neal *could* do it? What if he *did* like it? I might be back on a bike again!

I called the dealer to make an appointment for a test ride, but I tried not to get my hopes up. I remembered how Neal had hated my old Suzuki. The engine rumble that was music to my ears had been terrifying

continued on page 34

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Circle #289

After a long day of riding, "biker buddies" (left to right) Michael Knust, Mike Broadstreet, Don and Neal share laughs and a few drinks at Outlaws in Ouray, Colorado.

continued from page 18

noise to his. I'd never been able to coax him within 10 feet of my old bike. I had no idea how he would respond to a ride on the Gold Wing.

Test ride

Finally, the big day came. When I asked Neal if he would like to go for a ride on a Gold Wing, he said, "Yes." Of course, being a very agreeable kid, he usually says "yes" to everything.

At the dealership, we put on helmets and climbed on the cycle. I thumbed the starter button and listened as the engine murmured its soft idle. I glanced back at Neal, who was beginning to look a little nervous. We sat for a few minutes letting Neal get used to the sound of the running motor. When he seemed more relaxed, I clicked the Gold Wing into gear, and we glided slowly out of the parking lot.

We hadn't gone more than 100 yards when Neal started yelling, "No motorcycle!" He was scared, and he wanted off! But we were on a busy street without a good place to stop, so I had to get to the next intersection to turn around. Before we got there, the yelling stopped, and as we pulled up to the traffic light, I heard a tentative laugh behind me. I asked Neal if he wanted to go back to the dealer or keep riding. He exclaimed, "Keep riding!"

During the test loop, I looked in the rear view mirror and saw Neal grinning proudly. I pulled back into the dealership with tears in my eyes. This was going to work out after all!

Hitting the open road

We bought the very same Gold Wing we'd sat on a few days earlier—just in time for Neal's 14th birthday. We started out with short rides around the neighborhood. Then we

continued on page 22

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Circle #44

continued from page 20

went out on the highway; and pretty soon, my son and I were riding the back roads I had left behind years ago. We could ride all day and Neal loved every minute.

Still… this was a *touring* bike, right? Although Neal and I had never spent a night alone without Mom, we decided to take a ride down to San Diego and stay overnight—just to see if we were compatible. We were. And our real adventures began.

Neal and I have made many discoveries on the Gold Wing touring bike—London Bridge in Lake Havasu, "machaca" in Ensenada, the view of San Francisco from Treasure Island, airplanes racing in Reno, big trees in Sequoia, a volcano in Las Vegas, and that it can be very cold in Death Valley and very wet in Phoenix.

Five years later, riding is still Neal's favorite activity—and with him, it's mine too. Our best trip so far was a two-week Colorado tour in September 1995. Along with two other bikers, we rode 3,500 miles through all kinds of weather—even snow! More interesting than anything we did or saw was the way the other riders related to Neal; they joked around with him and treated him just like one of the guys. For the first time, Neal wasn't just a kid. In the evenings, after the bikes were put away, Neal even went out to the bars with us—of course, Coke was his beverage of choice.

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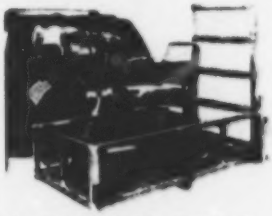
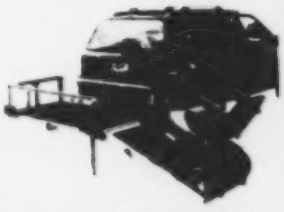


Safety first! Brake lights with signals. At just 125 lbs., it's easy to handle.



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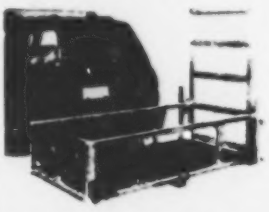
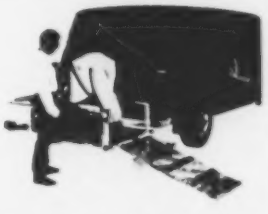


You're ready to go! Gate locks and straps hold the transport in place.



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Like father, like son: Don and Neal take a break to admire the breathtaking view of the Molas Divide during their September 1995 trip to Colorado.

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Gail and I understand the extent of Neil's disabilities. We don't expect that he will ever have a family of his own. We know he probably won't have the chance to live a "normal" life. But that doesn't mean his life can't be full and exciting. We constantly underestimate our son's abilities; he always surprises us with

continued on page 24

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Circle #200

"When I sold my old bike, I figured I'd never ride again," Don admits. But, with almost 37,000 miles under their belts, motorcycling is the favorite father-son activity of Don and Neal, pictured here in Colorado's Unaweep Canyon.

continued from page 22

what he can do and what he likes. The hardest part is for us to break through our preconceived notions.

When Neal and I are on the Gold Wing, we share a great experience on an equal basis. We see, smell, hear and feel the same things. Riding makes both our worlds bigger and better. And it always brings us closer together. **EP**

Don Cecconi, his wife, Gail, and their son, Neal, 19, live in Fountain Valley, California. Don is a national merchandising manager for Toyota Motor Sales USA; Gail is a counselor with the Comfort Connection Family Resource Center. Don and Neal belong to the Gold Wing Road Riders Association and ride their motorcycle together at least once a week. Described by his father as "one very busy young man," when not on the back of the Gold Wing, Neal divides his time between school, a job at the Sizzler Restaurant, bowling and baseball.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Familiar Faces

Olivia Davis, of Castro Valley, California, enjoys showing off her favorite outfit—a Cinderella dress! Olivia, who has congenital muscular dystrophy, enjoys going to preschool, riding her tricycle and playing with her Barbie dolls. Olivia's mother, Crista, wrote a *Search* letter (October 1995) hoping to connect with other families dealing with the same diagnosis. "We appreciate the many responses we received," writes Crista, "and we are very excited about corresponding with our new friends."

A new puppy is a lot of work, but four-year-old **Katie Lecker** does her part, providing eight-week-old Emily with a lap for cuddling and fingers to lick. Katie, who has spastic quadriplegia, lives with her parents, Wendy and Del, and older brothers, Sam, 9, and Scott, 7, in Albuquerque, New Mexico.

Play ball! The local airfield doubles as a ball park when **Zac Hochrein** and his father, **Wayne,** decide it's time for batting practice. "Zac is all smiles when it comes to ball games," writes his mom, Pam. "He loves skeeball, soccer and, especially, baseball with his dad." Five-year-old Zac, who has Down syndrome, lives with his parents and younger siblings, Luke, 3, and Kristina, 15 months, in Eden Prairie, Minnesota.

Derek Warman, 6, and his best friend, **Ginny Strutt,** 10, take Derek's new wagon for a spin. "Even though Derek's disability makes it hard for him to learn, he is still very clever," writes Ginny. "He knows just how to drive his mom crazy!" Derek, who has microcephaly, cerebral palsy and epilepsy, lives with his parents in Pittsburgh, Pennsylvania.

You can always pretend you're on vacation, as two-and-a-half-year-old **Annie McNally** demonstrates, wearing a grass skirt and doing the hula in her Redding, California backyard. Annie, who has cerebral palsy, lives with her parents, Enn and Brian, and her big sister, Frannie. When not "vacationing" in the backyard, Annie's busy weekday schedule includes half-day preschool and afternoons spent "helping out" around Mom's law office.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT? *Send it to: Readers' Photos,* EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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Total Communication And Assistive Technology

by Howard C. Shane

Q My eight-year-old daughter, who has cerebral palsy and is non-speaking, uses an electronic communication device that produces spoken messages. She controls the device by pointing to symbols with her index finger. Her pointing is accurate when she is not tired or distracted.

Although the electronic communication device seems to work fairly well, my daughter's speech-language pathologist at school has recommended that she use "total communication." What does this mean? Why can't my daughter just use her communication device?

A The concept of "total communication" was originally developed in deaf education and referred to the use of other methods of communication—such as writing, lip reading and speaking—to supplement the use of sign language. For non-speaking users of augmentative and alternative communication, total communication is an approach that encourages the development of a variety of communication strategies, rather than relying on one particular method. ("Augmentative and alternative communication," or "AAC," refers to any communication method that supplements or replaces non-existent, limited or difficult-to-understand speech.)

Total communication advocates encourage AAC users to develop multiple communication options and to use whatever works fastest and most efficiently in a given situation. For example, a total communication approach might include the use of a voice output communication aid like your daughter's, communication displays (boards with pictures, words and/or letters to which an individual can point), sign language, facial expressions, gestures and body movements. The ability to use a variety of communication techniques provides an individual with choices in different environments or situations. And when the primary means of communication does not work for some reason, total communication offers other techniques to use as a back-up.

Actually, everyone uses "total communication." Most of us use speech as our primary means of communication, but what about all the other ways we communicate—facial expressions, gestures, body movements and writing notes, to name just a few? For example, a nod of the head might be paired with the spoken word "yes," but it might also be used alone. Alternatives to speech might also be used when a person is unable to speak. For example, a person with laryngitis might use gestures and writing.

Children and adults who use AAC need to have the same choices. AAC techniques can be slow and frustrating for both user and listener; having options can significantly increase the speed of communication.

The school speech-language pathologist (SLP) is the most likely person to implement a total communication approach. In collaboration with parents, the SLP can decide on the methods of communication a child might use, based on an evaluation of the child's communication needs and abilities—including physical abilities, language development, learning skills, vision and hearing. For example, if your daughter has adequate manual dexterity, the SLP might teach her (and her family members) some basic signs to supplement her use of the voice output communication aid.

Your daughter may not have access to her voice output communication aid at all times; having the ability to use appropriate alternatives—such as facial expressions, gestures, communication displays and/or signing—can give her other options. Goals related to the development of different communication methods should be part of the overall SLP communication goals and should be written into your daughter's Individualized Education Plan (IEP).

The total communication approach is intended to help AAC users develop communication strategies that can supplement the primary means of communication—in your daughter's case, her voice output communication aid—not replace it. By developing multiple options, your daughter will further enhance her expressive communication abilities, thereby increasing her opportunities for successful, efficient communication. **EP**

In this regular department, questions from readers are answered by staff members of the Communications Enhancement Center at Children's Hospital in Boston. The clinic is directed by Howard Shane, Ph.D., a speech and language pathologist and a member of the EXCEPTIONAL PARENT *Editorial Advisory Board. Assisting in the preparation of this month's column was Kristi Peak Oliveira, M.S., a speech-language pathologist at the center.*

Since questions are answered without an interdisciplinary assessment, parents need to review any suggestions with appropriate professionals. Specific products are mentioned only to illustrate suggestions, not as endorsements.

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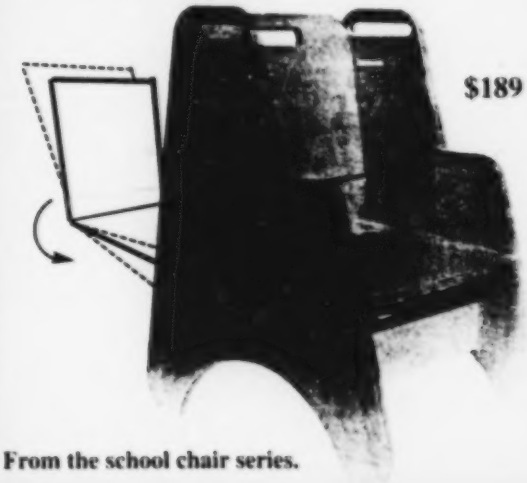

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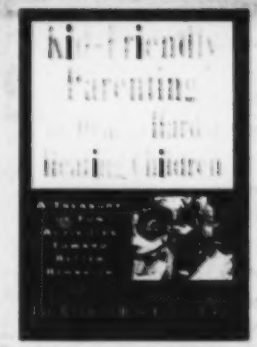

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Timothy Brei

A special connection

Timothy Brei, 39, is a developmental pediatrician at Indiana University Medical Center and Riley Hospital for Children in Indianapolis, Indiana. Brei, who has spina bifida, works specifically with children who have—or are at risk for—developmental problems. His patients include children who were born prematurely or have congenital disorders, children with cerebral palsy, and children and young adults with spina bifida, who are followed through Riley's large multi-disciplinary spina bifida clinic, where Brei spends much of his time. Brei, the son of a Lutheran minister, continues to be active in a local Indianapolis congregation, where he plays the organ and sings with the choir. He also enjoys theater and symphony performances. The following was adapted from an interview between Brei and EXCEPTIONAL PARENT *intern Tiffani Willis.*

Brei's father, Harlan, recalls how five-year-old Tim (shown here with cousin Linda Dierking, also 5) learned to ride a bicycle "after much struggling and many falls."

I was born in 1956, a time when many babies with spina bifida did not survive. That's because individuals with spina bifida often develop hydrocephalus, a condition that requires a shunt to drain excess fluid off the brain. That technology wasn't available until the late 1950s and early 1960s. But I was blessed to have had a family physician who forced the specialists to go ahead and repair my myelomeningocele—my back lesion. This physician basically told my parents, "If he doesn't survive, that's okay. But we're not going to just give up on him." So my myelomeningocele was repaired, and I did not develop hydrocephalus.

I grew up in several small Nebraska towns with my parents, Harlan and Dorothy, and an older brother, Nathan. My parents didn't cut me any slack because I had spina bifida. They refused to let me think of my physical problems as a handicap; they were determined to make sure I did everything I was capable of doing. They pushed me to pursue my musical interests. They helped me learn to ride a bicycle. They were just not going to allow me to be different than the other kids.

My father, who has an artificial leg, was a good role model in terms of demonstrating how one could adjust to having a physical problem. He was an adult when his leg was amputated at the thigh because of a bone tumor, but it happened before my parents got married, so I never knew him without his prosthesis. He never let his disability slow him down or keep him from doing something he wanted to do. That kind of gumption, that attitude, rubbed off on me.

Growing up

I don't remember having any kind of physical therapy as a child. Although I certainly walked later than typically-developing children, the level of my lesion was low enough that I could walk independently. My parents and family physician believed that the best therapy was just to allow me to do whatever I could do, which included attending a regular public school.

My education began in a two-room country schoolhouse near Scribner, Nebraska, where my family lived when I was born. My class—all three of us—occupied one room with the lower primary grades; the older classes were in the other. I remember playing with the other children on the swings, merry-go-round and our school's little baseball diamond. I certainly wasn't a good runner, but I was able to participate.

I went to junior high and high school in Sidney, Nebraska, a town of about 7,000 people. I often felt somewhat socially isolated. My physical difference was visible. It was obvious

I didn't walk the way other kids did.

I got involved with my peers through music and academic activities. I joined academic clubs like the honor society and math club, but my true avocation was music. By the time I reached junior high school, I was taking lessons on the piano and baritone horn. I also accompanied and sang with the junior high choir. I didn't get teased as much in high school, but neither did I develop many really close friendships.

Brotherhood

Growing up, my older brother, Nathan, and I were somewhat competitive. We were both good students, and I always felt driven to compete with him in the academic arena. I think it was a good kind of competition, but it wasn't something my parents fostered. I think it had more to do with me than with Nathan, who is three years older. It was just my personality.

Both Nathan and I attended my parents' alma mater, Midland Lutheran College in Fremont, Nebraska. By the time I arrived at Midland, Nathan was a senior, and all our old competitiveness had disappeared. We had both grown up, and we were able to develop a much closer and better relationship.

College was a liberating experience in many ways. Not only did I feel freed from the need to compete with Nathan, I also developed close friendships with other students. My disability didn't seem as important as it had in high school; college friendships were based on common interests, not on what I looked like. I felt much more accepted and comfortable.

Determined to succeed

At Midland, I completed a double major in biology and natural sciences. That academic background, combined with all my previous good experiences with physicians, made medical school seem like the natural next step. When I entered the University of Nebraska Medical School in 1979, I was the only student in my class with a visible disability. That made me all the more determined to succeed, and to succeed in such a way that people would not be able to say I had used my disability to get any kind of special treatment.

There is no question that medical school is difficult for everyone. Medical students have to learn an incredible amount of material in a very short time. But both medical school and residency were especially hard for me because I had a lot of urinary tract problems during that time. A few times, I had to be hospitalized.

And even when I was healthy, I didn't walk as fast as other people. I now use a scooter to get around the hospital; however, at that time, I just walked everywhere. In retrospect, I realize this probably contributed to additional fatigue, but I didn't recognize it then. My medical problems made it difficult for me to keep up, and I graduated from medical school a year late.

During high school, Tim immersed himself in his music, studying piano and baritone horn, and singing with the junior high choir.

Expectations and understanding

In my work with families, I try to help parents develop expectations that their children will succeed. Problems can arise when parents view children with disabilities as less capable. I sometimes run into families where the other children in the home have daily chores, but the child with the disability is not expected to do anything around the house.

Tim (right) and his brother, Nathan, provided the musical entertainment at their father's 25th ordination anniversary celebration, held at their father's church.

Children can also run into problems when parents try to protect them from everything that may be hurtful or harmful. It's natural to try to do that, but families can't isolate themselves or their children. I believe children with disabilities should be involved in activities, as early as possible, with children who don't have disabilities. This allows all kids to learn about differences at a developmental stage when they're more inquisitive and less purposely hurtful.

By the same token, it is important that a child with a disability learn about his or her condition and what it means. A child who understands his disability will be better able to

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handle teasing. I think it's also important for parents to remember that every child gets teased about something.

A special connection

I love my work. It's not that I often see sudden or rapid changes in individual children, but I feel great satisfaction in knowing that I am working to improve the lives of individuals with disabilities over the long term. I think my disability provides me with a sense of what families are going through. Of course, I know many pediatricians without disabilities who are just as compassionate, just as good at the medical issues and just as good with families.

I have to admit that I feel a special connection with families of children with spina bifida. One doesn't need spina bifida to be a stellar physician in the spina bifida clinic, but having spina bifida may lend me a bit of believability with both parents and children. I know how it feels to grow up with spina bifida. I know what it is like to be incontinent, and how it feels to be teased.

I always focus on helping parents find ways to make their children as independent as possible. It doesn't happen naturally; sometimes parents have to really push kids to do things for themselves. It's the same message parents hear from every physician in the clinic, but I think some of the families are more willing to listen to that from me. **EP**

Dr. Tim Brei is particularly proud of a booklet he and his colleagues put together for families of newborns with spina bifida or couples dealing with a prenatal diagnosis of a neural tube defect. "We wanted to give families a sense that children with spina bifida have a lot of capabilities," Brei explains. "So we added a lot of pictures of kids doing normal kinds of activities—the things any other child would do. We wanted families to know that a child's life can be good, even with a disability."

Photo courtesy of Indiana University School of Medicine, Medical Educational Resources Program

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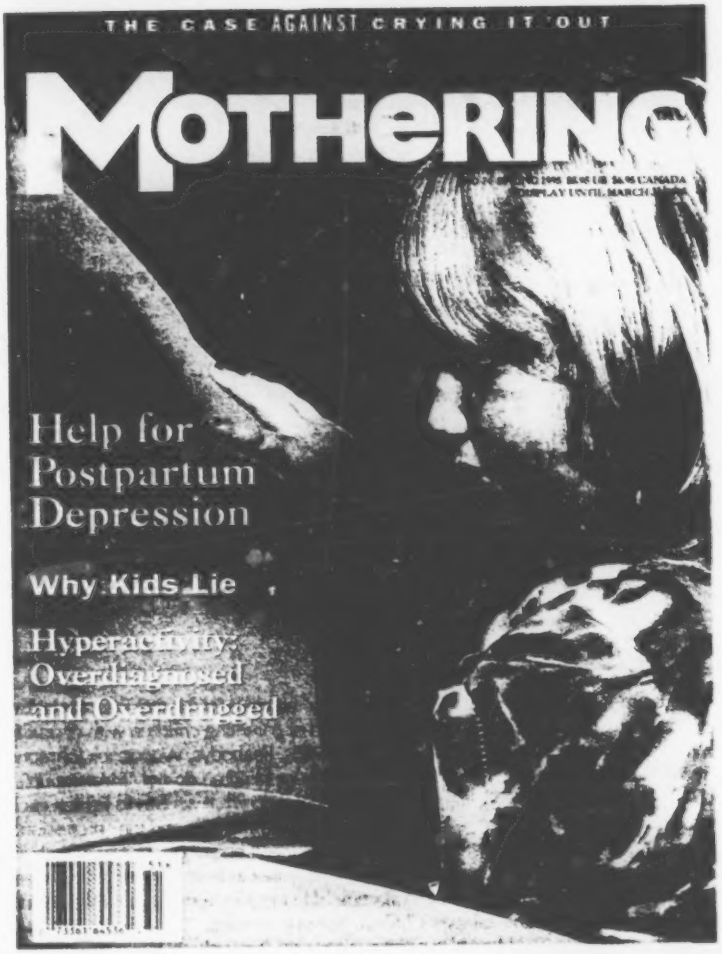

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Circle #293

10 Ways to Have More Fun at Your IEP

by Karen Esperanza & Patricia Powell

1. Wear costumes. On the meeting invitation, say, "Festive Dress Required."

2. As an equalizer, require all attendees to wear Groucho glasses.

3. Require all attendees to bring a musical instrument.

4. Provide refreshments: Jalapeño Cheetos and red Kool-Aid.

5. Invite Hillary Rodham Clinton. List her name on the cover sheet.

6. Try this introductory exercise: If you were a color, what color would you be and why?

7. Play background music—anything by Frank Zappa.

The Mothers From Hell

This advice has been provided courtesy of the Mothers From Hell. Don't let our name scare you: contrary to the suspicions of many school district personnel, we do not worship the devil, nor do we tolerate violence as a means of enforcing our children's legal rights.

We are, however, a loose-knit (more like velcroed—who has time to knit?) group of women who staunchly advocate for the rights of our children with disabilities. We use the name "Mothers From Hell" because we often feel labeled as such by the systems within our society that are obliged to offer appropriate services to our children, yet seem to have a terrifically hard time doing just that. We are the kind of parents who say things like, "This is not in compliance with IDEA," or "I'm looking for the least restrictive environment for my child, and I don't think it's the janitor's closet."

Our common bond is our children, all of whom have disabilities of one form or another... autism, cerebral palsy, Down syndrome, Enigma syndrome and DNOS (disorders not otherwise specified). We take our children's needs very seriously. As a group, we wrote a state Letter of Complaint that resulted in our local school district providing extended school year services for more than the (roughly) 3.7 children who had previously received services. We visit our state representatives and attend atrociously boring sub-committees, budget hearings and school board meetings. Yes, we are activists, and proud of it.

By now you may have noticed our slightly irreverent and cheeky attitude. It's called "humor," an element we feel is sorely lacking in this often depressing world of parenting children with disabilities. Faced with EEGs, EKGs, MRIs, Peabodys, Woodcock Johnsons and IQs, we are constantly told our children do not "measure up" to what is considered "normal." So we do what we can to lighten each other's load. We laugh; we poke fun at ourselves and the "professionals." We think laughter is good medicine. If one of our children lands in the hospital, we might gather together to lend comfort, encouragement, our complete collection of Harlequin Romance novels, macrame kits and left-over Clinique bonus cosmetics.

We believe there is strength in numbers. We believe parents need to support one another in life's struggles and joys. At times, we thought our group would bite the dust, but somehow we have managed to hang in there. Because none of us meet at our clothes-lines to gossip, or have lots of leisurely time for coffee clubs, we depend on our newsletter, "the Brimstone Bulletin," to serve as our voice and party line. "Confronting disability issues with combustible humor and sentiment" is the motto of our newsletter, which travels to more than 41 states—including such activist meccas as Kalamazoo, Michigan; Dunwoody, Georgia; Tewksbury, Massachusetts; Pepper Pike, Ohio; Seagrit, New Jersey; Fish Creek, Wisconsin and Old Dime Box, Texas—as well as the lost continent of Atlantis and the Bermuda Triangle. We welcome letters to the editor as well as articles on topics concerning disability issues. We do

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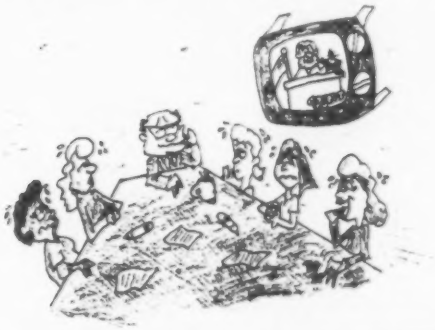
8. Give everyone a set of five flash cards to be used as the mood strikes:

- Who invited him?
- I love your hair! Where did you get it done?
- I'm sure we can trust that this will get worked out.
- Does the law have any bearing on this?
- Excuse me for 10 minutes while I call my lawyer.

9. Have TV in room tuned to the Court Channel.



10. Keep score: Give a really nice door prize to the IEP team member (parents excluded) who makes the most positive comments about your child. Award grand prize to the IEP team member who makes the most negative comments about your child—the winner gets to provide 36 hours of respite care, in their home, to your child.

Karen Esperanza has written numerous articles on disability issues. She is a vocal advocate for individualized programs for children with special needs. A founding member of the Mothers From Hell, Karen's motto is "preservation through humor."

Patricia Powell, founder of the Mothers From Hell, currently resides in Arcata, California. She is a student and the mother of two teenage children.

Illustrations by Frank Bernard, Jr.

not shy away from sarcasm or off-center humor; in fact, we encourage it! However, the editor reserves the right to publish with discretion.

We believe it is critical for parents of children with disabilities all over the country to lend mutual support to each other. We constantly get letters from parents who feel a crushing sense of despair and isolation. We wish we could answer them all personally. Although we are a support system for mothers, we respect the many roles played by fathers of children with disabilities and recognize that they, too, need support and support groups. Both mothers and fathers of children with disabilities have historically been silenced by an unnecessary shame. Our children are precious jewels; it is society that is disabled. Together we can create more accepting and inclusive environments for our children. But we can't do it alone.

Mothers From Hell is a grass-roots group. We have hobbled along on a shoe-string budget with funds raised from garage and bake sales, without having to sell our bodies and our souls. Recently, we were awarded a $6,000 grant from a local organization, The McKenzie River Gathering, to help fund a developmental disability sensitivity project and other endeavors. We are a non-profit organization in the process of getting tax-exempt status. Membership in the Mothers From Hell (men are welcome, too) is as easy as writing a check for $10. Having done that, you receive a subscription to the quarterly "Brimstone Bulletin." We also hawk marvelous tee-shirts ($15.95 each) as well as a start-up packet ($30), which includes information on how to form your own local Mothers From Hell group. Drop us a line. It doesn't matter if your sentences are incoherent; we speak that language, too. Together, our voices will be heard. Write to Mothers From Hell, P.O. Box 21304, Eugene, OR 97402.

—*Elizabeth K. Gerlach*

Elizabeth K. Gerlach is editor of the Brimstone Bulletin, *the quarterly publication of the Mothers From Hell. Ms. Gerlach is the mother of two children, the oldest of whom has autism. She is the author of* Autism Treatment Guide *(Four Leaf Press, 2020 Garfield St., Eugene, OR 97405; $11.95 includes postage), for which the Autism Society of America presented her with a 1994 "Outstanding Parent Achievement Award."*

Welcome to American Airlines

More and more Americans with disabilities are traveling by air. Last year, 1.5 *million* of American Airlines' and American Eagle's 85 million customers were travelers with disabilities.

To make flying as convenient and dignified as it can be for customers with disabilities, a panel of members of disability groups and a team of employees advises American and American Eagle on related customer service issues. The company recognizes that parents or individuals with disabilities are experts about their special needs for comfortable travel. Employees are trained to provide the level of service requested, and never to jump to their own conclusions about customer needs.

Although not required by federal law in most cases, pre-arranging for special assistance helps travel proceed more smoothly. Parents and individuals with disabilities can work with a travel agent or with the airline itself. American has specially trained Special Assistance Coordinators (at any American Airlines reservation number) who are always available and will call a customer who asks for special assistance several days before a flight to assist in planning.

American offers a wide variety of special assistance including TTY reservation services, assistance from the ticket counter to the aircraft, assistance to connecting flights, special seating, oxygen, Braille safety briefing cards and special meals. An on-board wheelchair is available on every jet to board customers who are unable to walk to a seat and for use to and from the lavatory. American also has doctors, board certified in aerospace medicine, to advise staff members if an individual's medical condition might be complicated by air travel.

Transporting mobility equipment
American provides storage for one collapsible, manual wheelchair in the cabin of each jet aircraft on a first-come, first-served basis. Otherwise, wheelchairs and scooters are stowed in the cargo area of the airplane. Customers using battery-powered wheelchairs or scooters are asked to check in at the ticket counter at least one hour before departure. American tries not to disassemble a wheelchair or scooter, but disassembly may be required. Customers can help airline staff by bringing a copy of the manufacturer's instructions for assembling and disassembling a battery-powered wheelchair or scooter.

Medications and oxygen needs
Medications should be carried in a carry-on bag. Since there are no refrigerators on board, consumers can let the Special Assistance Coordinator know if they will be carrying medication that requires refrigeration so appropriate accommodations can be made. When needles are used for injections, it helps to bring a copy of the doctor's prescription just in case security officers at airports have questions.

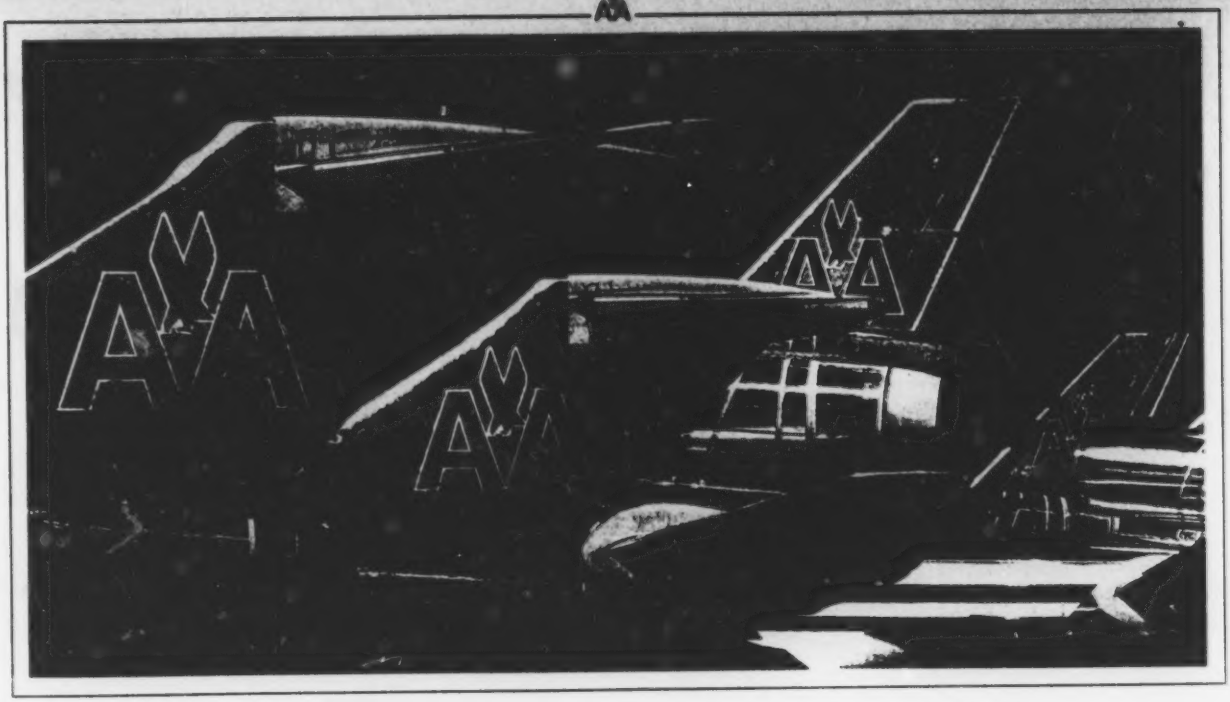
The Federal Aviation Administration (FAA) requires that oxygen on airplanes be dispensed only from FAA-approved containers available through the airlines. By calling a Special Assistance Coordinator at least 48 hours before the scheduled departure, travelers can explain oxygen needs. There is a charge for this service. Oxygen is not offered on American Eagle.

Service animals welcome
Service animals are welcome on flights, provided they do not block the main aisle of the aircraft. Some locations have quarantine laws for animals or prohibit their entry altogether. American or a travel agent can explain destination requirements.

Special meals
A wide variety of special meals are available. Flight attendants will open meal containers (but they are not required to help feed customers). Travelers need to check in advance with a travel agent or the airline to be certain a meal is offered on a particular flight; it may not be. For that reason, many travelers bring food.

Children can travel unaccompanied
Children with disabilities can usually travel unaccompanied under the same conditions as other children: five-year-olds can fly unaccompanied on non-stop flights; eight-year-olds are accepted for flights requiring connections. There is a nominal charge for Unaccompanied Minor Service for all children. Children who require extraordinary medical attention in-flight must travel with an adult. **EP**

In collaboration with the National Organization on Disability, Exceptional Parent is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.



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Circle #292

Access to the Skies

by Michelle Meacham

Even under the most ideal circumstances, air travel with children can be taxing. But the sky is not off-limits for a family planning a trip with a child who has a disability. Although obstacles will be encountered, planning and preparation can result in a safe and comfortable air travel experience.

Planning is key

Planning should begin even before reservations are made and tickets are purchased. Finding ways for children to participate in the vacation planning process can help to assure that arranged activities are appropriate for their interests and abilities. After making flight reservations, confirm seating assignments to guarantee that the family can sit together.

Children often benefit by being prepared for what they might encounter at the airport—crowds of people, security procedures and the roar of airplanes taking off and landing. Some families have found it useful to visit the airport prior to the planned date of departure.

Flying with mobility aids

Patience and preparation are the best tools for ensuring a safe and pleasant trip with children who use mobility equipment. When making reservations, inform airline representatives of the type of mobility aid a child or teenager uses. Ask about the airline's policies and procedures for handling mobility aids. Procedures vary from airline to airline, and it is important for parents to know how to prepare for the trip and what will happen to the equipment.

Foldable manual wheelchairs and other easy-to-store mobility aids can usually be stowed in the closets or other spaces on the aircraft. If the flight is crowded, however, they may be stored in the cargo hold, or belly, of the plane.

Flying with a power wheelchair or scooter presents unique challenges and requires extra consideration by both families and airlines. This discussion should begin when reservations are made. Know the dimensions of your child's chair; its height determines whether it can be transported in an upright position in the airplane's cargo hold or if it must be disassembled. It is also important to specify whether the chair uses wet-cell or gel batteries, as this will determine whether the batteries will be removed prior to shipment.

Families traveling with power chairs or scooters should try to give the airline 48 hours advance notice and arrive at the airport a minimum of one hour prior to the scheduled time of

California, Here We Come!

Flying was never something I intended to do. Besides, with a teenager in a wheelchair, it seemed impossible. Just pack up the mini-van, and we can go anywhere, but fly? No way!

But two summers ago, my 18-year-old daughter, Christina, was offered the chance to spend a week at an alternative and augmentative communication (AAC) camp in California—a bit too far to drive. A few phone calls later, our family was planning to spend two weeks in California. Christina would go to the Building Bridges Communication Camp during the first week of our vacation. We would spend the second week sightseeing.

We decided on a non-stop flight from New York to San Francisco. I would fly with Christina and her sister, Kristin; my husband, Mike, would join us for the second week.

What to pack? Clothing was the easy part, but what about Christina's adapted commode? I first tried to locate a medical equipment company in California from which we might rent a commode. But nothing panned out, so we decided to ship her commode by two-day express, in advance of our departure.

The big day arrived and—ready or not—we were on our way! Boarding was the most difficult part of the trip. First, Christina had to be transferred from her wheelchair to the aisle chair. But because of Christina's extensor tone, which causes her body to become rigid and extend, she had difficulty sitting in the aisle chair without a hip belt. Fortunately, I was able to use the quick-release belt I'd brought with me (on the recommendation of the airline) to use as a chest restraint in the plane. Then the flight attendant brought Kristin and Christina to our seats, while I disassembled the wheelchair so it could be stowed in the onboard closet. (Because this was not a crowded flight, the wheelchair did not have to travel in the cargo hold with the baggage.)

Sue, Mike and Christina enjoyed seeing the Golden Gate Bridge in August, 1994.

Christina had a great time at camp. For the second week, we rented a full-sized car— the rental price for a mini-van was more than double the car rate. We had to take the chair apart to transport it in the trunk; it was somewhat inconvenient, but not a major problem.

Our sightseeing included Muir Woods, Yosemite, Lake Tahoe and San Francisco. We spent a considerable amount of time just driving through Northern California; the scenery is magnificent.

Our air travel experience was far from the nightmare I'd anticipated. I wouldn't hesitate to fly to another distant adventure, but I must confess: I still prefer to drive!

—Sue Ankrom, Ritton, New York

departure so the ground crew will have time to properly prepare the equipment for shipment. Before leaving for the airport, label the chair with the type of battery it uses and attach a copy of the manufacturer's written instructions for disassembly and reassembly. These instructions are helpful to ground crews at both departure and destination points.

When reaching the security check on the way to the gate, parents may request a private security check. A security officer will accompany the family to another room where he or she will inspect their luggage and the equipment. Many families find these private security checks less stressful than leaving bags on the conveyor belt, with a line of impatient people forming behind, while a parent holds the child with a disability as the security officer inspects the chair.

At the gate, parents should receive a baggage claim tag for the equipment. Then they can wheel the child to the end of the jetway, where airline personnel will help transfer the child to an aisle chair.

At that point, the airline's ground crew will begin preparing the chair for shipment. If the wheelchair uses a spillable wet-cell battery and cannot be stored in an upright position, Department of Transportation (DOT) rules require its removal and storage in an approved battery box. The acid-like substance in a wet-cell battery is considered hazardous material, and a spill could create a problem.

Batteries should not be separated from power mobility equipment unless necessary to meet DOT hazardous materials rules. If the chair can be loaded, stored, secured and unloaded in a upright position, DOT prohibits removal of the battery, regardless of type. Some airlines feel it's better to err on the side of caution and may have a policy of removing all batteries, both spillable and nonspillable. Parents can challenge such policies, which frequently result in the unnecessary removal of batteries, thereby increasing the potential for damage to both batteries and chairs.

Frequent Flyers, Frequent Hassles

Demi's family at Disney World, Orlando, Florida, 1995.

Our family of frequent flyers usually takes six to eight trips a year. Air travel has been our primary mode of transportation for vacations and family visits to relatives spread across the United States. When my youngest daughter, Demi, was an infant and her sister, Austin, was a slightly older toddler, the three of us even traveled without my husband.

As Demi got older, things became considerably more complicated. Demi, who has congenital muscular dystrophy, has extremely weak trunk and head control. She uses a wheelchair that has been specifically designed to meet her positioning needs. The wheelchair separates into seat and base; the seat functions as an approved car seat. Unfortunately, this seat is too big to fit into a coach-class airline seat. Demi does not have enough head and trunk control to sit independently.

When she was younger than two, this wasn't a problem. I carried her onto the plane and held her on my lap. But once she turned two, Federal Aviation Administration (FAA) regulations required that she occupy her own seat. When I explained that Demi could not sit independently, we were advised to fly her on a stretcher via medical transport.

But Demi was medically stable and did not need medical transport; furthermore, she was still small enough to sit on my lap. When I asked for other alternatives, airline officials offered none. The problem has yet to be resolved, so I have resorted to "pretending" Demi is still younger than two.

I also have run into problems at the security gate, where I am usually asked to remove Demi from the wheelchair. One time, I was forced to lay Demi on the floor, walk through security myself, then come back to get her and walk through again with her.

When this request was made again recently, I refused to remove Demi from her chair. The security guard became quite insistent, and I insisted on speaking to a manager. After several minutes, during which time a long line formed behind me, a manager came and inspected Demi's wheelchair while she remained seated.

We love to travel and plan to continue. However, I have decided that it is too exhausting to fight these battles all by myself. If my husband cannot accompany us, I will have to drive. Next month, our family plans a ski vacation. The ski resort has had no difficulty coming up with accommodations that will allow Demi to attend ski school. We're just waiting to see what the airlines have in store.

—K.E., Alabama

At your destination, the equipment should be waiting by the time all passengers have disembarked. If disassembled for transport, it should be reassembled with the battery attached. All mobility aids must be returned in their original condition.

Know your rights

The 1990 DOT regulations on enforcement of the 1986 Air Carrier Access Act (ACAA) require that individuals with disabilities "receive consistent and nondiscriminatory treatment when traveling by air." Discrimination might include refusal to allow a person with a disability to board the plane, requiring that a passenger with a disability be accompanied by an attendant, refusing to allow a service animal to travel in the cabin area or refusing to make an aisle chair available. Again, however, most problems can be avoided by informing the airline of a child's specific needs in advance.

If parents encounter what they believe is a violation of the ACAA, their first step is a discussion with the airline's complaints resolution official (CRO). Contact can take place at any point, even during the reservation process. Parents can ask any gate agent to summon a CRO; one is to be available at all times. The CRO is empowered to act on behalf of the airline he or she represents; only a pilot can overrule a CRO decision, and an overrule must be based only

continued on page 50

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on safety considerations.

If discussion with the CRO does not result in a satisfactory resolution of the problem, parents can request a written response from the CRO. Later, if a written complaint to the airline is submitted, this response should be included, along with all other pertinent information, including the CRO's name and the date of the incident in question. The law requires an airline to answer any written complaint within 30 days of receipt, but it is not obliged to respond to any complaint dated more than 45 days after the alleged violation.

When filing a written complaint, notify DOT's Aviation Consumer Protection Division (400 Seventh St. SW, Rm. 10405, Washington, DC 20590; 202/366-5957, voice; 202/755-7687, TTY). Parents also have the option to file formal complaints and civil law suits. The above suggestions may exceed the requirements of the ACAA, but the more prepared the parent is, the easier the trip will be. For more information on your rights under the ACAA, call the Paralyzed Veterans of America at (800) 424-8200, ext. 709, and request this free brochure: *The Air Carrier Access Act: Make It Work for You.*

Share your experiences

Access to the Skies, a program of the Paralysis Society of America (PSA), wants to hear air travel stories. This project is collecting information to find out how well airlines are complying with the ACAA. More than 500 people have responded to the survey, which continues through the end of August. To participate, call PSA at (800) 643-8245, 8–4:30 (central time), weekdays, or participate by visiting PSA's Internet web site at http://www.computek.net:80/access95. **EP**

Michelle Meacham works as a project coordinator on Access to the Skies, a project funded by the Paralysis Society of America, a subsidiary of the Paralyzed Veterans of America.

Trouble-free Traveling

Tony Reed sits in his stroller on his favorite ride at Disney World—the All-American Train.

In January of this year, my husband and I decided to take our 11-year-old son, Tony, on a long-awaited trip to Disney World.

Tony, who has cerebral palsy, uses a power wheelchair. But because we would have no way to transport his power chair around Orlando, we took his large, specially designed fold-up stroller.

At the ticket counter, we checked our bags and were told to wheel Tony to the boarding gate, where we could give his stroller to an attendant. We wheeled Tony down the ramp to the entrance of the plane and then gave the stroller to an attendant, who tagged it "special handling." The flight attendant told us the stroller would be stored in the belly of the plane; after we landed, they would bring it up and have it waiting for us. She offered us the use of an aisle chair to get Tony to his seat, but I found it easier and faster to carry him.

The busy flight attendant found time to check in with us twice, just to make sure we had everything we needed. When we landed, Tony's stroller was right where they said it would be—all set up and ready to roll.

On our return trip, the departure was delayed. The pilot gave Tony a bag of games, puzzles and toys to pass the time. When we disembarked to change planes, the stroller was waiting.

All in all, we found air travel a great way to go. Airline employees were courteous and caring. Flight personnel spoke directly to Tony, not around him—something that happens a lot. Everyone treated us with respect and kindness.

—Mary Ellen Reed, Wellsville, Ohio

Ground Transportation

Renting an accessible van once you get there

There's good news for families who want to rent a wheelchair- or scooter-accessible van for a day, a week, a month or longer. Although none of the major car rental agencies can accommodate such a request, two companies—Wheelers, Inc. and Wheelchair Getaways—provide accessible van rentals at many locations across the country.

Van rental prices depend on location and time of year, and they may include delivery charges and local sales tax. A one-week, June rental of a fully accessible van in San Francisco, for example, will cost a total of $550–650, which includes sales tax, delivery and airport drop-off. (A comparable weekly rate for a full-sized automobile is $200–250.)

Be sure to reserve your van as early as possible, especially for popular destinations and during peak travel periods.

- **Wheelers, Inc.** (7101 N 55th Ave, Glendale, AZ 85301; 800/456-1371 or 602/435-8392; 602/435-9989, fax) offers delivery to airports in 29 states and Washington, DC. In about 40 cities, Wheelers works directly with Avis Rent-A-Car. Wheelers offers a variety of van configurations with capacity for up to three wheelchairs, automatic ramps or lifts and nylon tie-downs, and hand controls or other modifications.
- **Wheelchair Getaways** (PO Box 605, Versailles, KY, 40383; 800/642-2042) offers delivery to major airports and other convenient locations in more than 100 cities in 20 states. Wheelchair Getaways offers full-size vans with lifts and mini-vans with ramps, with capacity for one or two wheelchairs; all have nylon tie-downs. Hand controls and other modifications are also available.

—Naomi Angoff Chedd

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Visit EXCEPTIONAL PARENT and Meet

Editor In Chief

Stanley D. Klein, Ph.D.

at

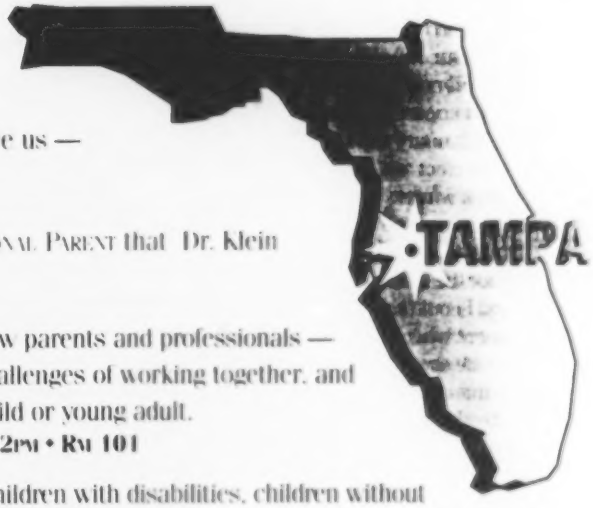
ABILITIES EXPO

Florida State Fair Expo Park, Tampa, Florida

Booths 125-127

May 3-5

Stanley D. Klein, Ph.D., clinical psychologist, educator, co-founder and Editor In Chief of EXCEPTIONAL PARENT magazine, will be at Abilities Expo in Tampa, along with other members of the EXCEPTIONAL PARENT team. Please drop by to see us — we welcome your insights and ideas about our magazine.



And don't miss any of the vital seminars sponsored by EXCEPTIONAL PARENT that Dr. Klein will lead:

- **Parent/Professional Collaboration**. A discussion of how parents and professionals — health care, educational and others — can overcome the challenges of working together, and improve their relationships for the ultimate benefit of the child or young adult.

  FRI. & SAT. 11AM • SUN. 12PM • RM 101

- **Improving Everyday Family Relationships**. Parents, children with disabilities, children without disabilities, grandparents, cousins — they're all involved. Dr. Klein will lead a discussion of how to deal with the unique challenges of raising a child with a disability or special health care need.

  FRI. & SAT. 1PM • RM 101

- **Planning For The Future**. It can be frightening, especially for parents of a child with a disability. A discussion of current opportunities, and of how parents and professionals can work together to create new possibilities.

  FRI. & SAT. 3PM • SUN. 1:30PM • RM 101

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SEE YOU AT ABILITIES EXPO!

Booths 125-127, Florida State Fair Expo Park, Tampa, May 3-5.

Say It Ain't So, Minnie

A dream vacation turns into a struggle for accessibility

by Barbara J. Boelter

Five-year-old Shannon and 10-year-old Justin enjoyed meeting "Chef Dale."

Disney World! John and I had gone there on our honeymoon. This would be our first *real* family vacation. Our children, Justin, 10, and Shannon, almost 6, were now old enough to appreciate the wonder of it all, and a January trip to Florida seemed like the perfect antidote for a cold Minnesota winter.

Shannon was the biggest Disney fan in our family. She had dressed as Minnie Mouse for the last two Halloweens, and John and I could hardly wait to watch her amazement when she came face-to-face with the life-sized counterparts of the stuffed animals in her room. We knew she would be able to enjoy them just the same as any other five-year-old. You see, the Disney characters don't talk, and Shannon is profoundly deaf. From our previous trip, talking with friends, and extensive reading, I did know that Shannon would need an American Sign Language (ASL) interpreter to fully enjoy certain attractions at the Disney theme parks.

ASL is Shannon's language. We began signing to her when she was just five months old, as soon as we found out she was deaf. When she was 11 months old, we got her a part-time deaf baby-sitter so she could acquire her first language more naturally. She began attending a preschool for deaf children before she turned two, and she now attended a full-day kindergarten program at the Metro Deaf School in St. Paul, one of only a few schools in the country with a bilingual/bicultural curriculum, where the language of instruction is ASL, and English is taught as a second language.

Five-year-old Shannon was already quite savvy as to how to interact with an interpreter. She had successfully worked with interpreters at swimming lessons, birthday parties and other community activities. She had attended interpreted productions of several local theater companies and other community events where interpreters were provided by the event sponsors.

The script-and-flashlight solution

Although it was only August, the compulsive organizer in me wanted to start planning our January trip to the sun and fun of Orlando. Besides, I knew that having a deaf child *always* requires extra planning. Shannon wouldn't need an interpreter to enjoy many of the rides and attractions at Disney World, but I knew the enjoyment of several tours and live performances depended on understanding spoken English. I assumed only certain of these performances would be interpreted and wanted to plan our trip around Disney's schedule.

I first had to find out which attractions were interpreted. I assumed there was a department, or at least a single employee, responsible for coordinating these services. Three months and numerous phone calls later, I was "officially" informed of Disney's policy for accommodating guests like Shannon: They would provide my five-year-old with a written script for all tours and performances and a flashlight that would allow her to "read along" with those performances held in darkened auditoriums. Shannon is a pretty bright little girl, but she reads only as well as most kindergartners. The script-and-flashlight solution did not seem to constitute what would be considered appropriate accommodations for a deaf adult, let alone a child.

Disney also sent me their "Guidebook for Guests with Disabilities," which shows where wheelchair-accessible rest rooms are located, gives information on rides for guests with physical disabilities, and denotes attractions that provide amplified headsets for hard of hearing guests. Finally, the booklet explains that a guided "foreign language" tour with an ASL interpreter would be available for the nominal fee of $45 an hour. (I find it interesting that *American* Sign Language is considered foreign!)

My calls to Universal Studios and Sea World were cheerfully returned by Guest Services representatives, who helped select the day we would visit. They would provide an interpreter at no charge!

"Not Disney!"

Dismayed by Disney's response, especially in comparison with these other two attractions, I called legal advocacy groups in both Minnesota and Florida. I also contacted private interpreters in Florida to ask what I was doing wrong. Despite my three months of phone calls, perhaps I still hadn't spoken to the right person.

No such luck. Disney's lack of responsiveness to deaf and hard of hearing guests was apparently well known in the

deaf and interpreting communities, though not well publicized outside this small circle. While my hearing friends reacted with shock and disbelief—"Not Disney!"—deaf friends shared experiences eerily similar to my own.

A study in contrasts

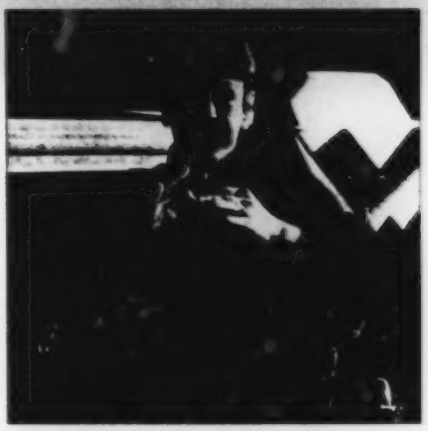
Once we arrived at Disney World, we found the employees to be genuinely interested in our needs and surprised when informed of the "corporate" policy. We did accept Guest Services' offer of a Special Assistance Pass, which they provided so we could sit through shows twice in case Shannon missed something the first time. The pass allows the holder to enter attractions through special entrances, thus bypassing any lines. I was vehement in informing Disney that our acceptance of the pass did not mean we accepted it as providing accessibility for Shannon.

Not every attraction lends itself to live interpreting; however, I could envision a way to make most accessible to deaf visitors. For example, we saw many "pre-shows," displayed on numerous TV screens at the same time, but none were captioned. This was disappointing, not only because captioning is so readily available but also because this service would benefit many more people than just those guests who are deaf. This lack of accessibility is even more surprising considering the amazing technology utilized at some of the Disney events.

In contrast, the days we spent at Universal Studios and Sea World were a delightful experience. Both attractions demonstrated their view of appropriate accommodations and showed how easily such accommodations can be made. The interpreters took us into the appropriate shows first, making most efficient use of their time and leaving us to enjoy the other attractions on our own later. Shannon didn't feel overlooked and, in contrast to the performances at Disney, she got *all* of the information (I may be a pretty good signer, but I am *not* an interpreter). Also, for the first time on our trip, I was able to relax and appreciate the shows as a guest. I could enjoy watching Shannon and Justin enjoy the attractions, which is what a mom should do.

The right thing to do

As parents of children with disabilities, it is our obligation to educate ourselves about the laws protecting our children's rights. As the parent of a child who is deaf, I have come to expect that I will have to "educate" small organizations about their responsibilities; many are simply unaware of their obligations. After almost six years of the Americans with Disabilities Act (ADA) and the increased sensitivity and awareness that has come with it, there are still those for whom my daughter is the first deaf person they have encountered. I know, however, that is not the case with Disney World.



Barbara, as interpreter, needed to find a seat where Shannon's line of vision could include her and the stage. At one performance, the only available seat was a wheelchair.

But even without the legal protections of the ADA, isn't providing an interpreter to a child who is deaf just the *right* thing to do? Isn't this the image Disney tries to portray? Don't they want a five-year-old girl, who just happens to be deaf, to enjoy her heroes as fully as any other child? Some day Shannon will know this all happened, and, if I am right, Mickey and Minnie will owe her an apology. **EP**

Barbara Boelter, her husband, John, and children, Justin, 10, and Shannon, 6, live in Eagan, Minnesota. Barbara is on the board of directors of the PACER Center, Minnesota's Parent Training and Information (PTI) program, and volunteers at the Metro Deaf School. John is an attorney and is involved with the Minnesota Foundation for Better Hearing and Speech.

Statement From Walt Disney World

The Walt Disney World Resort has made extensive use of written aids, which continue to be improved regularly and are available for every show, ride and attraction at its theme parks. In addition, the Resort is planning to offer interpreting services for live performances in the near future. Further, open caption on video monitors is now being implemented in several attractions, with more to come.

Shannon was thrilled to meet the life-sized counterparts of her stuffed animals.

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Pediatricians and parents agree: the needs of children and adolescents are quite different from those of adults and require special facilities, professional experience and training, and support programming.

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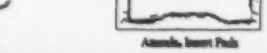

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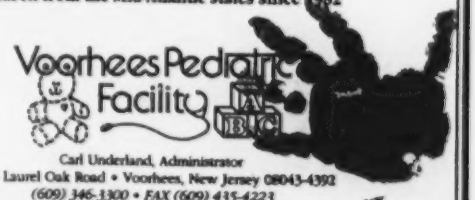

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Summer Abroad or at Home

I Faced My Fears

by Joel Symons

During the summer of 1995, I went on a two-week trip to Eugene, Oregon, to participate in the Mobility International USA (MIUSA) Youth International Leadership and Disability Rights Exchange. I was sponsored by the State of Alaska's Department of Developmental Disabilities and supported by Challenge Alaska and the Juneau School District.

I decided to participate in the program because I wanted to expand my knowledge and get to know different people. I wanted to learn to be accepted by other people. I was representing the community of Juneau, Alaska. I wanted to make things better for myself and my friends in Juneau. I wanted to be able to tell the representatives in the Alaska legislature that they must support people with disabilities.

Before the program, I was afraid to talk about my disability. I have Down syndrome, and I know I have to go through life with my disability whether I like it or not. But I feel my disability is not the issue. I believe I should have the same rights as other adults. People have feelings. They should cooperate with others. Life has to be a give-and-take situation.

Joel Symons (center, in black tee shirt) shakes it up with other young MIUSA delegates during a diversity celebration held during the 1995 Youth International Leadership and Disability Rights Exchange in Eugene, Oregon.

My other fear was that I didn't know who I could trust to help me out when I had questions.

I didn't know how to deal with my fears about the program, so I just participated and worked hard. Each day there were different activities including disability training, leadership workshops, community service projects and recreation activities. I liked all of the events, except for some of the recreation activities.

The acceptance from the MIUSA staff was great. I felt loved. The hardest thing was learning how to communicate with people who spoke different languages.

The major thing I accomplished during the MIUSA program was that I faced my fears. I gained acceptance from other people. I received love from the staff when I had a hard time. I am now a member of MIUSA. I want to volunteer to help others, and I hope to participate in an exchange again.

Joel Symons, 21, who has Down syndrome, is currently finishing high school in Juneau, Alaska.

To Russia With Change

by John Dreiling

"You're going where?"

"Be careful!"

"Aren't you scared?"

"Oh, you're so brave!"

These are just a few of the comments I heard when I told people I would be spending three and a half weeks in Russia as a member of the Mobility International USA (MIUSA) Russian Culture, Language and Disability Rights Program.

Many people still think of Russia as the birthplace of communism, our enemy during the Cold War, and a place to be feared. Today, however, Russia is undergoing major political, economic and cultural changes. Groups like MIUSA—which sponsors international, educational exchange programs—are working to improve the lives of people with disabilities around the world, and to replace distrust with cross-cultural understanding.

Guided by the MIUSA philosophy—"challenge yourself and change the world"—our group started on our long journey. Our Russian host was the Adventure Club of Moscow, an organization that arranges expeditions, trips and adventures.

After landing at Moscow International Airport, we were led down a hall bordered on one side by a wall of glass and, on the other, by a wall of people. Our group of about 20 people—five in wheelchairs, three who were deaf, and one with a visual impairment—received piercing gazes from passersby as we

Continued on page 47

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continued from page 45

traveled this hallway. We felt like rats going through a maze, watched intently by a group of science students. I had butterflies in my stomach.

It was a sign of things to come. Our group attracted attention wherever we went. Our colorful wheelchairs and positive attitudes were something rarely seen in Russia, where people with disabilities—called "invalids"—are often kept in their apartments due to a combination of cultural attitudes and architectural inaccessibility. (In the city of Tver, for example, my wheelchair and I had to be carried up a flight of stairs to reach my host family's "first-floor" apartment.)

Now, back in the United States, I ask myself how those three and a half weeks affected me. To answer this question I need to reflect on my experiences in Russia. Those experiences made me aware of the fact that the progress made by people with disabilities in the U.S. came about only because people spoke up. If people do not continue to speak up, we could stop making progress, even lose many of the advances we have made so far.

John Dreiling, front and center in his pink wheelchair, smiles among MIUSA friends at the Women's Club in Tver, Russia during the 1995 Russian Culture, Language, and Disability Rights Program.

My travels in Russia made me realize the difference we can make just by living our everyday lives. Just being out and about, just being visible as people with disabilities—these things can change attitudes. In Russia, we rarely saw people with disabilities out on the streets; and when we did, it was usually someone begging for money.

I learned that it is important for people with disabilities to speak with a single voice. We have the best chance at success if we join together rather than split up into small groups.

Most importantly, I learned that people are people all across the globe. We all struggle with the same things. We can and should support each other in striving to make a better world! **EP**

John Dreiling, 21, lives in Eugene, Oregon, where he is an intern at MIUSA. Dreiling has spina bifida.

Leslie Gilbert helps to build an accessible trail as part of a community service project undertaken by MIUSA Youth International Leadership and Disability Rights Exchange delegates.

About Mobility International

This summer, Mobility International USA (MIUSA) is offering educational exchange programs in Mexico, Russia, and right here in the United States. Individuals from all over the world (ages 15–34), with or without a disability, can apply to participate.

The application procedure involves providing some general information and writing essays. Trips cost $800–1300, depending on distance traveled. MIUSA will work on a case-by-case basis with each qualified delegate to accommodate individual needs. Orientation materials will be provided in alternative text formats, and interpreters will be provided during each exchange. Scholarships are available. Once MIUSA receives completed application(s), a telephone interview will be scheduled.

MIUSA accepts motivated individuals who are involved in their communities and are interested in both sightseeing and participating in a challenging schedule of cultural and educational events.

Participants, or "delegates," will have the opportunity to learn new languages, get involved in community development and live with a local "homestay" family, where they can observe and participate in the family's everyday life and cultural traditions. MIUSA provides lectures and field trips to help delegates learn about disability rights and diversity issues in other countries.

This summer's programs are tentatively scheduled as follows:

- **The Mexico Leadership, Minority and Disability Rights Exchange** (June 25–July 16), for youths and young adults aged 16–24, will include Mexican cultural events, visits to historical sites, meetings with local disability rights activists and the experience of living with homestay families.
- **The Russia Culture, Leadership, Language and Disability Rights Exchange** (June 25–July 16), for teenagers aged 15–18, will include Russian language classes, meetings with Russian disability organizations, participation in outdoor activities and visits to cultural and historic points of interest in Moscow and surrounding areas.
- **The Young Adult Leadership and Disability Rights Exchange** (July 1–27), for ages 21–34, and **the Youth International Leadership and Disability Rights Exchange** (August 13–27), for ages 15–20, will be held in Eugene, Oregon. Activities for both programs will include seminars on disability and leadership issues, recreational and sports activities, team-building workshops and community service projects.

For more information or an application, contact MIUSA at (541) 343-1284 (voice/TDD), (541) 343-6812 (fax) or miusa@igc.apc.org (e-mail).

—Aliscia Niles & Christa Bucks

Aliscia Niles is the Mexico Program Coordinator and Christa Bucks is the Public Relations Coordinator at Mobility International USA.

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Circle #240

Powered Wheelchair or Scooter: How Do You Decide?

by Naomi Angoff Chedd

"Wheelchairs provide better trunk support..."
"Scooters cost less and look great..."
"Wheelchairs come in more colors..."
"Why don't more kids use scooters?"

Having your child evaluated for powered mobility is never an easy undertaking. These comments from therapists, manufacturers and parents clearly illustrate the differing opinions on the subject. In most cases, a wheelchair can accommodate a child's positioning, comfort, safety and mobility needs—even for a child with severe physical limitations and complex needs. But for many children, a powered scooter is also an option.

Upper body control a must

Although professionals and parents look at powered mobility from different perspectives, all seem to agree that scooter use requires a child to have relatively good trunk and head control and some manual dexterity in at least one hand. Some children with spinal cord injuries or spina bifida may be good candidates for scooters, while a child with quadriplegia, who needs a lot of head and trunk support, might be better accommodated in a wheelchair. "We don't often think to put little children in scooters," acknowledged one physical therapist. "Maybe it's time we did."

Where do you begin?

Every parent and child wants powered mobility that is safe, comfortable, easy to maneuver and good-looking. What should you be thinking about? What questions should you ask? And what's readily available? The guidelines at right will help you get started. **EP**

Guidelines for comparing powered wheelchairs and scooters

	Wheelchair	Scooter
Head and Trunk Support	Customized head and trunk support equipment that can accommodate most physical conditions and abilities.	Seat belts, arm rests and lateral supports are available, but typically provides fewer support options.
Seating	Numerous options.	More options than in the past, but more limited than wheelchairs; however, some may accommodate seating systems. Seat swivels away from scooter, providing more freedom to drive up to tables, desks and sinks of different heights and shapes.
Controls	Numerous options, including joysticks, foot controls, head controls and sip-and-puff switches.	Adjustable standard tiller controls power and steering. Fewer options; joysticks available from some manufacturers.
Speed and Maneuverability	Adjustable speed; easy to maneuver on hard surfaces, such as wood floors and sidewalks, as well as softer surfaces, such as carpets and grass.	Adjustable speed; front-wheel-drive option (good for hard surfaces) or rear-wheel drive (better for grass and dirt); may require more space and be harder to maneuver in tight quarters, but easier for transfers to chairs, beds and toilets.
Stability	Four-wheeled with anti-tipping device.	Most are three-wheeled; four-wheeled version available from some companies.
Tilt in Space	Available.	Not available, although a seat that reclines slightly is now on the market.
Colors	Good variety—at least 10 colors.	Fewer colors—about 5.
Transportability	Cannot be folded; van with ramp or lift is a necessity; adapted interior with tie-downs, lowered floor and/or raised roof is often needed. Adaptations can be expensive.	Can be disassembled and has removable seats; fits in the trunk of most standard-sized cars or on outside-mounted racks.
Access to Public Transportation	All accessible public transportation vehicles have wheelchair lifts and tie-downs.	ADA requires accessible public transportation vehicles to have appropriate tie-downs for scooters, but many do not.
Cost	$4,000–12,000 or more, depending on customized positioning, support, seating and control equipment.	$2,000–5,000, depending on customization; almost always less expensive than wheelchairs.
Insurance Coverage	Most health insurance providers cover all or most of the cost of a power chair if it is prescribed by a medical doctor.	Obtaining insurance coverage may be a little more difficult. Prescription must come from a medical doctor and be carefully phrased so as not to sound like a recreational vehicle. One manufacturer recommends calling them "platform mobility aids" rather than "scooters."

Thanks to the following people for their comments and contributions to this article: Bob Boyd, Bruno Independent Living Aids, Inc., Oconomowoc, WI; Wally Bringold, Amigo Mobility International, Inc., Bridgeport, MI; Barbara Hodge, RPT, Needham MA; Caroline Larson, OTR/L, Bedford, MA; Priscilla Osborne, RPT, Boston, MA; Mick Scaramuzzi, Medi-Rents, Inc., Waltham, MA.

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Self-Advocacy For Family Caregivers

Four principles from the National Family Caregivers Association

by Suzanne Geffen Mintz

What does it mean to be a happy person when you are a family caregiver? How do you stand up for yourself, take care of yourself and find a balance between your own needs and those of your loved ones? These are heady questions, and ones we have discussed often at the National Family Caregivers Association (NFCA), because they are at the core of our search for meaning and our need to have a code to live by.

We've given form to many of these ideas in NFCA's "Principles of Caregiver Self-Advocacy." They are the fundamental tenets by which we now try to live; we hope that you, too, can use them as guideposts:

1. CHOOSE TO TAKE CHARGE OF YOUR LIFE. We caregivers often feel as if all choice has been taken away. We ask, "Why did my child (or spouse or parent) have to have a disability (or get sick or have an accident)? Why did this happen to our family? Why did it happen to me?" We so often feel out of control.

But having a sense of control, or choice, depends as much on our attitudes as on our circumstances. As long as you are alive and mentally competent, you have the freedom to choose. You may not be able to control the course of a disability or disease, or the effects of an injury, but you can control how you live with it. You can let it take over your life, or you can let your life progress, incorporating your loved one's disability into it. You may not have all the choices you once did, or you may now have to make choices you don't like, but if you recognize your power to choose, and you consciously act on your choices, you won't feel quite as much like a victim anymore.

2. HONOR, VALUE AND LOVE YOURSELF. If you are like most caregivers, you are constantly worn out and questioning yourself, but don't doubt yourself for a minute. You're doing a great job! And you owe it to yourself to take very good care of yourself and to love yourself.

Think about the safety messages you hear on a plane during takeoff. The flight attendant tells you, "If the cabin loses pressure, an oxygen mask will drop down from the bulkhead. If traveling with a small child, or someone else who needs assistance, put your own mask on first."

That safety message is a metaphor for your life as a caregiver—you can't help someone else if you are gasping for air yourself. You can't give and give without renewing your energy. We fill our cars with gas when they are on empty. Can't we be at least as good to ourselves?

3. SEEK, ACCEPT AND, AT TIMES, DEMAND ASSISTANCE. Sixty-five percent of family caregivers tell us they don't get any help from family or friends. But that may be partly because we don't always ask for help, or don't accept assistance when it is offered.

Friends often want to help but may not know how. We've all heard people say, "Call if you need anything." It may not sound like they mean it, but what can you lose by asking?

Sometimes, people just need a concrete suggestion about what actions might be helpful. Next time try saying, "I need you now. Could you stay with Jack while I go get a haircut on Saturday morning?"

You don't have to be a martyr. You have a right to ask for help, and you have a right to be angry when you don't get any. Don't be afraid to stand up for yourself.

4. STAND UP AND BE COUNTED. There is strength in knowing you are not alone; there is power in numbers. Family caregivers represent more than 10 percent of the adult population in this country. Nobody knows exactly how many family caregivers there are, but estimates range from 18 to 25 million. We are everywhere, but we are largely invisible.

The women's movement pointed out the subtle, and not so subtle, societal inequities that have kept women down. We believe we need a similar caregivers movement—a movement to gain recognition, to broaden services, to educate ourselves and to provide each other with support. There is a wonderful feeling of empowerment that comes from standing up for yourself and recognizing your own worth. You are not alone; millions share your concerns and feelings.

A powerful force for change

Family caregivers can be a powerful force for change in their own lives, and in the lives of their loved ones, if they are willing to be their own advocates. We hope you will use these principles to take control of your life, to honor, value and love yourself, and to find the help you need. Together we can gain recognition and benefits for ourselves and for all caregivers across this great land. **EP**

Suzanne Mintz has been a family caregiver for more than 20 years. She is the president and a co-founder of NFCA, a not-for-profit membership organization dedicated to improving the quality of life for family caregivers. For information, contact NFCA, 9621 E. Bexhill Dr., Kensington, MD 20895-3104; (800) 896-3650; (301) 942-2302, fax.

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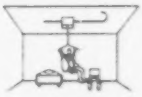

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Circle #35

PART ONE

Guardianships and Other Protective Assignments

by Frank L. Brunetti

Q Our 14-year-old son has moderate to severe mental retardation, but is in relatively good physical health. He attends a special pre-vocational training program in our school district.

When our son is an adult, we believe he will need help managing his everyday life, so other people do not take advantage of him. We have prepared a will so that the property and money we have designated for him will go to a special needs trust, leaving him eligible for government support programs.

We have been told we should also appoint a guardian or conservator as soon as possible. But we thought that would take place after our deaths. Do we need to appoint a guardian or conservator while we are still alive? If so, why?

A You have taken appropriate steps to provide financial support for your son by creating a will and special needs trust (SNT); however, he is still not prepared for your deaths. The SNT trustee you designated will have the power to "supplement" benefits your son receives and use the trust income or assets in a variety of ways (see "Trusts for Children With Disabilities," February 1996). And, should your deaths occur before your son is a legal adult, the guardian appointed in your will would have the authority to act on behalf of your son—but only until he reaches legal adulthood.

But what happens after that? Who will look after your son? Who will have the legal authority to manage his personal finances and any government benefits he receives? Before your deaths, it is important to consider choosing a guardian or conservator who would have the authority to make decisions your son is unable to make, both before and after he is an adult.

If you believe your son would be considered "incompetent" in the eyes of the court—defined as being "of unsound mind and unable to manage his affairs"—you should consider beginning the process of appointing a "guardian." A guardian has the same legal authority and responsibility as a parent; this person would have authority over your son (called the "ward") and his property, and would be legally responsible for him.

If, on the other hand, you believe your son will be able to manage his day-to-day affairs but be unable to care for his property, you should consider appointing a "conservator." A conservator would have authority only to manage your son's property.

Both guardianship and conservatorship proceedings take place through the court.

Responsibilities of a guardian

The guardian controls the property and person of the ward in the same way that parents are responsible for their minor children. The difference is that the guardian acts with the approval and supervision of the state. The guardian can determine where and how the ward will reside and can give consent for medical and professional care. The guardian becomes the trustee of the ward's property. On the ward's behalf, the guardian may make expenditures for support, maintenance and education; purchase property and engage the services of professionals.

In some states, such as New Jersey and California, the guardian may even make gifts and revoke a revocable trust. These special powers can have significant estate planning benefits and may reduce potential estate taxes before a ward's death.

Because their powers are extensive, guardians are held to a high standard. The state can remove a guardian for mismanagement of a ward's assets, for failure to carry out duties, for being convicted of a felony, for conflict of interest (for example, if the guardian or the guardian's company benefits from buying or selling the ward's assets) or for other causes.

Soon after appointment, the guardian must file an inventory of the ward's financial assets with the court. In New Jersey, for example, guardians must file an inventory within 60 days of appointment; in California, they are given 90 days. Some states, such as Massachusetts, require the guardian to file an inventory, but do not specify a time frame. Thereafter, the court will periodically require a guardian to provide an "accounting," a full disclosure of financial transactions made on the ward's behalf.

A guardian must maintain financial records that provide a complete picture of the guardian's financial activities. Poor record-keeping will subject the guardian to questions from concerned family members, potential beneficiaries and the court who made the guardianship appointment. EP

In Part Two of "Guardianships and Other Protective Assignments," which will appear in the May issue, I will discuss the process of appointing a guardian and the option of appointing a conservator.

In this column, attorney Frank L. Brunetti answers questions about any aspect of estate planning involving a child with a disability. Mr. Brunetti, a Professor of Law and Taxation at Fairleigh Dickinson University in Teaneck, New Jersey, has written extensively on the topic of estate planning for families who have children with disabilities.

Send questions to: ***Estate Planning,*** *EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

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Coverage for a Person with Epilepsy

by Richard Epstein

Q We live in Pennsylvania. Our son developed epilepsy at the age of nine. He is now 24 years old and no longer covered under our family's health insurance policy. He is in excellent health, but requires twice-a-year blood tests to monitor therapeutic levels of his anti-seizure medication.

The company he now works for refuses to insure him although they are taking a deduction for the insurance premium out of his paycheck. Initially, his employer said he would have a six-month wait for coverage to begin because of his "pre-existing condition." But more than a year has passed, and he is still not covered.

Routine medical appointments and medications are very costly. Do you have any suggestions?

A There are really three separate questions here: The first is whether a person can be excluded from coverage in an employment-based group health insurance program because of a pre-existing condition. The second is whether a premium can be deducted from an employee's paycheck for health insurance coverage when the employee is not participating in the group health insurance program. The third question, I think, is whether it is possible to obtain health insurance for a person with a condition such as epilepsy.

According to the Epilepsy Foundation of America, obtaining insurance can be a major problem for people with epilepsy. However, aside from self-funded plans, which are regulated by federal law (see *Health Insurance Troubleshooter*, July 1995), health insurance is regulated on the state level, so the answer to the first two questions would usually depend on the state in which an individual lives.

Some states have passed health insurance/health care reform laws, which often require that employers who offer group health insurance must offer coverage to *all* employees in the group, regardless of medical history. A waiting period of six months to a year for a pre-existing condition is allowed; however, expenses unrelated to the pre-existing condition must be covered as soon as the policy takes effect.

Pennsylvania has a series of regulations on this issue and on the question of whether a health insurance premium can be deducted from the paycheck of an employee who is not participating in the group health insurance program. However, each case must be individually evaluated. Your son can call the Pennsylvania State Insurance Department's Bureau of Consumer Services (717/787-2317) for an individual evaluation of his situation. (If dealing with a self-funded plan, however, your son should contact his local Protection and Advocacy office, Disability Law Center or local legal services office for advice. For local offices, contact the National Legal Aid and Defense Association: 202/452-0620; 202/872-1031, fax.)

If contact with the State Insurance Department does not result in a satisfactory solution, the next step would be to call the Epilepsy Foundation of America (800/332-1000). This self-help group provides information to people with epilepsy, and may be able to offer additional advice.

Your son has a number of options to explore. Although it may be too late in his case, it is often possible to extend an existing health insurance policy through provisions established by COBRA. Under COBRA regulations, a young person who is no longer entitled to health insurance coverage under his parents' policy may be able to extend that coverage on a temporary basis. A further extension can sometimes be granted for a person with disabilities.

When a health insurance policy is extended under COBRA regulations, the individual generally pays the insurance policy premium, plus a small administrative fee. There may be further charges during an additional, disability-related extension period. The right to coverage under COBRA regulations, however, must usually be exercised at the time the child first becomes ineligible for coverage under his parents' policy. For detailed information, call the United States Department of Labor (202/219-8784).

Your son may also be eligible for an individual policy from a private insurer, or for a policy issued by a fraternal, social or parents' group. The Arc's group health insurance program is one such example (see *Health Insurance Troubleshooter*, March 1995). For more information, call the Albert Wohler's Company (800/323-2106).

It is also important that your son writes to his state legislators to describe his health insurance problems. It is vital that legislative representatives have the opportunity to hear directly from consumers about health insurance issues. **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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WHAT'S HAPPENING

Dental Care for Individuals with Disabilities

The National Oral Health Information Clearinghouse (NOHIC), a service of the National Institute of Dental Research, focuses on the oral health concerns of individuals with disabilities and special health care needs. NOHIC develops and distributes information and educational materials on special care topics, maintains a bibliographic database on oral health information and materials, and provides information and referral services, with a staff trained to respond to specific interests and questions.

For information or a complete listing of publications, contact the National Oral Health Information Clearinghouse, 1 NOHIC Way, Bethesda, MD 20892-3500; (301) 402-7364; (301) 907-8830 (fax); nidr@aerie.com (e-mail).

Survey Looks at Needs of Parents with Disabilities

With funding provided by the National Institute for Disability and Rehabilitation Research of the U.S. Department of Education, Berkeley Planning Associates (BPA) is conducting the first-ever national Needs Assessment Survey to gather information about the challenges faced by parents with disabilities. It is hoped that the results will better inform public policy and initiate improvements to the service system. Participants in the survey will receive a free subscription to the newsletter *Parenting with a Disability*, published by Through the Looking Glass (TLG), and access to TLG's parent hotline and network. BPA, in cooperation with TLG, the Raleigh (North Carolina) Center for Universal Design and the World Institute on Disability, operates the Research and Training Center on Families of Adults with Disabilities.

To participate in the survey, contact Sabrina Williams, Berkeley Planning Associates, 440 Grand Ave., Suite 500, Oakland, CA 94610; (800) 897-0272 (voice); (510) 465-4493 (TTY); bpa_rtc@dnai.com (e-mail).

Publications

• *Toys and Play: A Guide to Fun and Development for Children with Impaired Vision* is a 56-page booklet describing the use of toys and games to stimulate the curiosity of infants and toddlers with visual impairments. The booklet describes widely-available or easily-made toys and ways to motivate children to explore their surroundings more confidently. The booklet is available for $10 from: Publications Department, Lighthouse Industries, 36-20 Northern Blvd., Long Island City, NY 11101 (make checks payable to "The Lighthouse, Inc.").

• The Cleft Palate Foundation publishes several booklets and pamphlets for parents of children with cleft lip/palate. *For Parents of Newborn Babies With Cleft Lip/Palate, Cleft Lip and Cleft Palate: The First Four Years, Cleft Lip and Cleft Palate: The School-Aged Child, Information for the Teenager Born With a Cleft Lip and/or Palate, Feeding an Infant With a Cleft* and *The Genetics of Cleft Lip and Palate: Information for Families* are available for $2 each; the foundation also has a number of informational pamphlets that are available at no charge. To order, or to receive a full listing of publications, contact the Cleft Palate Foundation, 1218 Grandview Ave., Pittsburgh, PA 15211; (800) 242-5338; (412) 481-0847 (fax).

FUNNY AS A CRUTCH by Frank Bernard, Jr.

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Circle #282

Speech Apraxia

by David Hirsch, M.D.

Q My daughter is seven years old and has been diagnosed with encephalopathy—a degenerative brain disease—that is now static; that is, it is not getting any worse. She has developmental delays and mild cerebral palsy, mostly affecting her left arm and leg. She can walk and feed herself. She is in special education classes but will be mainstreamed into a few typical classes soon.

Her most significant problem is an almost total lack of intelligible speech. She tries to talk but can't seem to form the words. However, she seems to understand what people say to her.

Her speech problems are so frustrating for her—and the rest of the family—because she tries so hard and gets upset when she cannot express her thoughts. Her father and I are concerned that she will just give up and not want to talk at all. Do you have any suggestions? I have heard that some medications may be useful for this problem.

A Most of us never really think about the complexity of everyday communication. For example, the brain's ability to comprehend speech (receptive language) involves hearing sounds, segmenting those sounds properly as words, and then matching those words with their appropriate meanings. The ability to use speech to express thoughts and ideas (expressive language) is controlled by a different part of the brain. This is one reason receptive and expressive language may develop at different rates. This is also why individuals like your daughter may be able to understand spoken language without having expressive language skills.

Your daughter seems to have what is called speech apraxia. (An apraxia is a loss of the ability to carry out familiar, purposeful movements or activities in the absence of motor or sensory impairments.) Unfortunately, speech apraxia in a child is often more of a problem than in an adult (who might have lost the ability to speak because of a stroke, for example). This is because young children with speech apraxia usually do not have an already-developed language base, as would be the case with an adult who developed this condition.

I know how frustrated your daughter must be; I have seen similar frustration in some of my own patients. It sometimes seems that the harder a child tries to overcome this type of apraxia, the more difficult it becomes to speak. And research has shown that after eight years of age, it becomes less likely that a child will show any significant improvement with this type of speech difficulty.

There have been reports of certain drugs having a positive effect—antihistamines in some cases, and a medication known as Levodopa in others—in rare cases where the speech apraxia was actually caused by a type of dystonia (abnormal movements or coordination due to disordered muscle tone). This type of drug therapy is not uniformly accepted by neurologists and is often difficult to manage. A pediatric neurologist would have to evaluate your daughter to determine if she has the type of speech apraxia that might be helped by drug treatment.

Based on my experience, and that of neurologists and speech therapists with whom I have worked, it seems that using augmentative and alternative communication (AAC) would be the best approach for your daughter at this time (see "Getting Started with Augmentative Communication," May 1995; "Total Communication and Assistive Technology," page 28). AAC includes all types of communication that supplement speech—sign language, picture or letter boards, computers and voice output devices.

Parents (and some professionals) often worry that AAC use means "giving up" the hope of oral communication. This is not true. AAC is intended to supplement any speech the individual has or may develop. The main role of AAC is to allow a non-speaking child more active and fulfulling participation in everyday life. I suggest that you seek an AAC evaluation for your daughter at the nearest university medical center.

An AAC evaluation begins with assessments of your daughter's vision and hearing. Next, she will be evaluated by a speech pathologist and occupational therapist who have experience with AAC. After these evaluations are concluded, the AAC team—you, your husband and the professionals—will meet to make decisions about the AAC device or technique that may work best for your daughter. You may also want to involve your daughter's school district and her case manager in the division of developmental disabilities. These agencies may even be able to pay for AAC devices or therapies. **EP**

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT'S Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd. in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005, (617) 730-8742 (fax).*

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MEDIA

Something's Not Right: One Family's Struggle with Learning Disability

by Nancy Lelewer

REVIEWED BY TEDDI SOBIN

SOMETHING'S NOT RIGHT: ONE FAMILY'S STRUGGLE WITH LEARNING DISABILITY by Nancy Lelewer (Vander Wyk & Burnham) is available through Exceptional Parent Library, (800) 535-1910; $14.95; Item No. VB133LD.

I have always been riveted by the stories told by parents of children with disabilities—stories of births, accidents, illnesses, diagnoses, school problems; stories of challenges overcome. The situations in these stories are always different from mine, but the feelings are the same. These stories unite me with others and inspire me to face my own challenges creatively.

That's why *Something's Not Right*, by Nancy Lelewer, was such a good read. It's the autobiographical account of Lelewer's discovery that three of her four children had learning disabilities. Her son also had speech and gross motor problems. The story takes place in the sixties and early seventies, when little was known about learning disabilities, and even less was actually done to help children with learning disabilities learn.

Lelewer was an involved parent. She talked to dozens of experts, researched methods and schools, and even created her own games to teach her son basic concepts. All of Lelewer's children became productive citizens with rewarding careers. In the final chapter, she outlines today's view of learning disabilities, explains how she wrote her book and recommends resources for further study.

Lelewer's account, which chronicles more than 20 years, is presented in a concise and readable manner. She also includes photographs of her children. By the time I was finished, I felt like Lelewer could be my next-door neighbor or an old friend from college. I heartily recommend this book not only to parents of children with learning disabilities but also to anyone needing the inspiration to persevere and find creative approaches to their own challenges.

Theodora (Teddi) Sobin and her husband, Anthony, own an art gallery in Santa Fe, New Mexico, and parent two spirited children. Their oldest child, Nicholas, 9, was born with a heart defect and has speech and gross motor delays. Teddi is a graduate of Partners in Policymaking and is an "Adobe volunteer," assisting other parents with IEP concerns.

The Face of Inclusion

REVIEWED BY MARGIE LESSEN

"The Face of Inclusion: A Parent's Perspective" (Joenro, Inc.) is available through Exceptional Parent Library, (800) 535-1910; $99; Item No. JR1320D-Video.

"The Face of Inclusion" provides an in-depth view of the life of a family who made great efforts to provide as "normal" an education as possible for their daughter with a disability. The video contains information helpful to administrators, teachers, support staff and families—anyone trying to decide what is best and what really works for a student with a disability.

While the focus of the video is the middle school experience, the information is relevant for all grade levels. The video stresses the importance of providing special education support to the general education program so the inclusion model will be effective and successful.

The video's message is that when we offer alternatives to traditional programs, we must look carefully at the special needs of students and the way these needs can best be served on an individual basis.

Margie Lessen received a Master's Degree in Special Education from the University of New Mexico in 1975. She teaches at Hubert Humphrey Elementary School in New Mexico. She is married and the mother of two children.

Parents and professionals at Parents Reaching Out in Los Lunas, New Mexico, are now serving as media reviewers.

NEW MEDIA

Coming in May

FROM BARRIERS TO BRIDGES: A COMMUNITY ACTION GUIDE FOR CONGREGATIONS AND PEOPLE WITH DISABILITIES edited by Ginny Thornburgh *(National Organization on Disability) is available through Exceptional Parent Library, (800) 535-1910; $10; Item No. ND157OD.*

"INCLUDE US" (Tiffhill Productions) is a video for children of all ages, featuring young performers—some with disabilities—singing songs about inclusion. It is available through Exceptional Parent Library, (800) 535-1910; $19.95; Item No. LS158OD.

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Networking

Information from The National Parent Network on Disabilities

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Welcoming Diversity

People with disabilities live in all types of communities and settings, and come from a variety of cultures. More and more, the disability movement is reflecting this diversity, as well as finding ways to help traditionally unserved and underserved families get services for their children. Many communities, both urban and rural, already face tremendous challenges such as poverty, illiteracy and crime. Though it can be difficult to make inroads into these communities, the disability movement recognizes their importance and has made it a goal to welcome the strengths, gifts and differences people from these communities can offer.

PTIs REACH OUT

In 1990, a revision of the Individuals with Disabilities Education Act (IDEA) instituted a requirement that the boards of all Parent Training and Information Centers (PTIs) include parents and professionals who are members of minority groups. PTIs—funded by the Division of Personnel Preparation, Office of Special Education Programs in the U.S. Department of Education—help parents to understand their children's specific needs, communicate more effectively with professionals, participate in the educational planning process and obtain information about relevant programs, services and resources. In addition, the revised version of the IDEA provided funding for "experimental projects," in which PTIs would work with parents in traditionally underserved or unserved communities, both urban and rural.

Experimental projects have allowed PTIs to develop community networks, create training materials that reflect positive, multicultural images of people with disabilities and their families, and train professionals on issues of cultural diversity. Experimental projects also offer workshops and one-on-one support to help parents participate in the development of appropriate Individualized Education Plans (IEPs) for their children.

South Central Los Angeles and New Orleans are two areas in which experimental projects are underway. In South Central, Loving Your Disabled Child (LYDC, 4715 Crenshaw Blvd., Los Angeles, CA 90043; 213/299-2925) offers educational workshops, dramatic presentations, a family resource library and parent support group meetings. LYDC also provides telephone support in times of crisis, and gets parents involved in training other parents to be peer counselors. The Pyramid Parent Training Project in New Orleans (3132 Napoleon Ave., New Orleans, LA 70125; 504/895-5970) uses a holistic approach to helping families with special needs; they develop individualized service plans for these families and refer them to other useful resources. Raising parents' awareness of their rights regarding special education is another prime focus of Pyramid Parent Training's efforts. In each of these cities, experimental projects are helping to counter the neglect that the communities have traditionally had to endure.

At the MultiLingual Center in Paterson, NJ, young adults with disabilities show off their talents and boost their self-esteem by performing in holiday pageants. The MultiLingual Center, in partnership with SPAN, provides bilingual training to parents of children with disabilities.

In the spring of 1995, representatives from 16 experimental projects created Grassroots, a national, multicultural consortium of community parent resource centers. The consortium aims to promote leadership development within underserved communities. Grassroots publishes *Tapestry*, a newsletter highlighting the activities and winning strategies of community organizations throughout the country.

PTIs have also taken steps to increase diversity in their own offices by expanding boards of directors, hiring new staff members and recruiting new volunteers. Some PTIs have established satellite offices in urban neighborhoods, Native American communities and

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reservations, and rural and remote areas. They have translated and created resource materials to address the languages and cultures of dozens of groups. They have joined forces with coalitions, advocacy groups and community service agencies to mobilize resources and expand and coordinate services. Here are just a few of the projects that have reached more than 150,000 parents in over 50 culturally diverse communities throughout the country:

North Carolina moves ahead

North Carolina's Exceptional Children's Assistance Center (ECAC, P.O. Box 16, Davidson, NC 28036; 800/962-6817; 704/892-1321; 704/892-5028, fax) is forging partnerships with other service organizations such as the Sickle Cell Disease Association of Piedmont (SCDAP, 1102 E. Market St., Greensboro, NC 27420-0964; 800/733-8297; 910/274-1507; 910/275-7984, fax). ECAC staff members are excited about participating with the SCDAP in monthly teleconference discussions involving parents and professionals from across the state.

ECAC has also started two new parent groups—Across All Cultures and Minority Involvement for Exceptional Children. Across All Cultures is a support group comprised of parents from different backgrounds who work to educate others about cultural differences. Minority Involvement for Exceptional Children is a support group for African-American parents who are often in the minority at support group meetings for specific disabilities. In addition, ECAC has created *Faces*, a newsletter for Spanish-speaking families. Parent training materials have also been translated into Spanish.

Advocacy on the Alaskan airwaves

Alaska's Parents As Resources Engaged in Networking and Training Statewide (PARENTS, 540 W. International Airport Rd., Ste. 200, Anchorage, AK 99518; 800/478-7678; 907/563-2246; 907/563-2257, fax; parents@corcom.com, e-mail) is pursuing on-going plans for including diverse and underserved groups in training sessions—especially rural, Native American families. PARENTS has been reaching these families by translating written materials into oral Native American languages and then disseminating the information via radio broadcasts that can be received in rural parts of the state.

PARENTS has also reached many families through collaboration with local school districts and human services agencies. Upon requests from school boards, staff members have conducted parent training sessions and served as family advocates during the IEP process. These efforts have produced concrete results—a recent statewide conference was attended by a number of parents from traditionally underserved communities.

Diversity in Minnesota

In Minneapolis, staff members at PACER Center (4826 Chicago Ave. S., Minneapolis, MN 55417-1098; 800/537-2237 or 612/827-2966, voice/TTY; 612/827-3065, fax; mnpacer@gteens.com, e-mail) are also reaching out to parents of diverse cultures. For example, staff members from Southeast Asian backgrounds have held six workshops, developed a videotape for professionals and translated training materials into Southeast Asian languages, and an African-American staff member leads a support group for African-American parents of children with attention deficit hyperactivity disorder (ADHD). PACER has also developed culturally-appropriate resource materials for Native American families on issues including fetal alcohol syndrome/fetal alcohol effects (FAS/FAE). A Native American parent advocate is now working with families in the Detroit Lakes area and other communities. Finally, PACER is working with local families to assist in developing programs and resource materials for the Hispanic community.

Empowering parents in Mississippi

In Mississippi, Empower, a new program of Parent Partners (3111 N. State St., Jackson, MS 39216; 800/366-5707; 601/366-5707; 601/362-7361, fax) serves families in the rural, impoverished Mississippi delta region. Empower works with small groups of parents, providing information about disabilities, helping families find useful services and offering parent-to-parent matching.

Parent Partners, with the Coalition for Citizens with Disabilities, co-sponsored a training conference that attracted more than 300 participants—well over half were members of minority groups. In addition, Parent Partners now provides more effective assistance to individual families by using resource materials reflecting the cultural diversity of families served.

Satellite offices span New Jersey

In New Jersey, satellite offices of the Statewide Parent Advocacy Network (SPAN, 516 North Ave. E., Westfield, NJ 07090-1446; 800/654-7726 or 908/654-7726, voice/TTY; 908/654-7880, fax) are reaching underserved communities. Offices in Newark and Paterson serve Hispanic and African-American parents primarily. Bilingual staff members and resource materials are available to Spanish-speaking families.

SPAN's main office also has many resources for parents from diverse ethnic backgrounds. As part of a collaborative relationship with the New Jersey Department of Health, SPAN staff members work part-time in statewide health department offices providing parent-to-parent support for families whose children have recently been diagnosed with a disability. They help these families find support groups and obtain appropriate educational assistance and other services. SPAN also works with local organizations, such as Head Start and teen pregnancy centers, to publicize available services. These outreach efforts have been successful; SPAN served 7,000 clients last year, and 25 percent were members of minority groups.

The effort is just beginning...

Though these efforts have succeeded in increasing services to families from all backgrounds and communities, the PTIs acknowledge that much more remains to be done.

NEW PRODUCTS

WALKERALLS JR.

WalkerAlls Jr. are carrying pockets that attach to the side or back rails of pediatric walkers. Each pouch has two pockets, specially sized for small hands. WalkerAlls Jr. are available in a variety of bright colors, with or without decorative coordinated trim.

Adamo Industries, Inc., Memphis, TN 38122

Circle #294

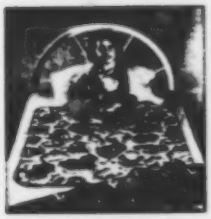
FEEL & FIND

Feel & Find is a tactile matching game designed for children with visual and cognitive disabilities. The set includes 22 pairs of wooden shapes and tiles. Children can use Feel & Find to play numerous games alone or in groups—increase the number of pieces to increase the difficulty level. A cloth carrying and storage bag is included.

Guidecraft Inc., Garnerville, NY 10923-0324

Circle #295

SNOOZY'S WATERPROOF SHEET PROTECTOR



Snoozy's Waterproof Sheet Protectors are quilted pads that keep linens and mattresses dry in the event of nighttime incontinence. Each pad is 34 x 35 inches, with four quilted layers for comfort and absorbency. The pads can be bleached and machine washed and dried. The sheet protectors are available in two different patterns—one depicting the adventures of Snoozy the Bunny and his friends, the other solid white for older children.

PRIVA Inc., Anjou, Quebec, Canada H1J 1K8

Circle #296

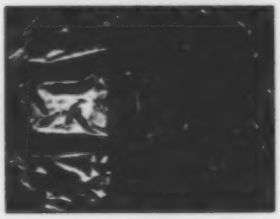
MERRY WALKER PEDIATRIC AMBULATION DEVICE

The Merry Walker Pediatric Ambulation Device, designed for use by children who lack balance but desire the independence of walking, features a folding steel frame, washable seat, mesh back and mesh side pocket. The wide, weighted base promotes stability. The Pediatric Ambulation Device is available in small, medium, large and extra-large sizes to accommodate children from 35 to 55 inches tall.

Merry Walker Corporation, Northbrook, IL 60062

Circle #297

JAY GS PRESSURE RELIEF FLUID PAD



The GS Pressure Relief Fluid Pad adds pressure relief capability to the Jay GS growth positioning cushion. The patented Jay Flow fluid in the pad conforms to the user's shape and moves with the user, providing maximum contact while reducing pressure and shearing. Unlike foam or gel, Jay Flow fluid does not tend to return to its original shape. The pad requires no maintenance other than periodic cleaning and is available in both pediatric and adult sizes.

Jay Medical Ltd., Boulder, CO 80301-2537

Circle #298

DRESSEZ

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Arcor Industries, Escondido, CA 92029-1008

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 58) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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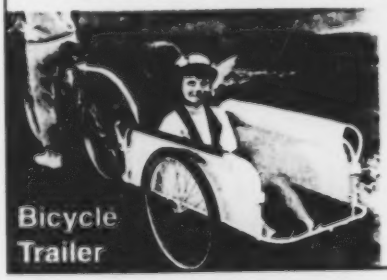

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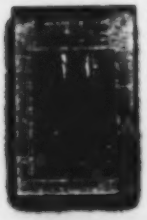

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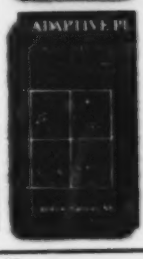

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"Chef Andrew," above, enjoys a kindergarten cooking activity.

Seven-year-old Timothy Sterry (far right) says he loves his younger brother, Andrew (right), "more than going to Disney World."

Andrew

by Timothy Sterry

My little brother's name is Andrew. He is five years old. Andrew is funny. He makes me laugh when he makes funny faces.

I read lots of stories to my brother. He sits next to me when I read *The Little Red Hen* and *Little Red Riding Hood.*

My brother snores at bedtime. I cannot sleep when he snores. Sometimes I say, "Be quiet!"

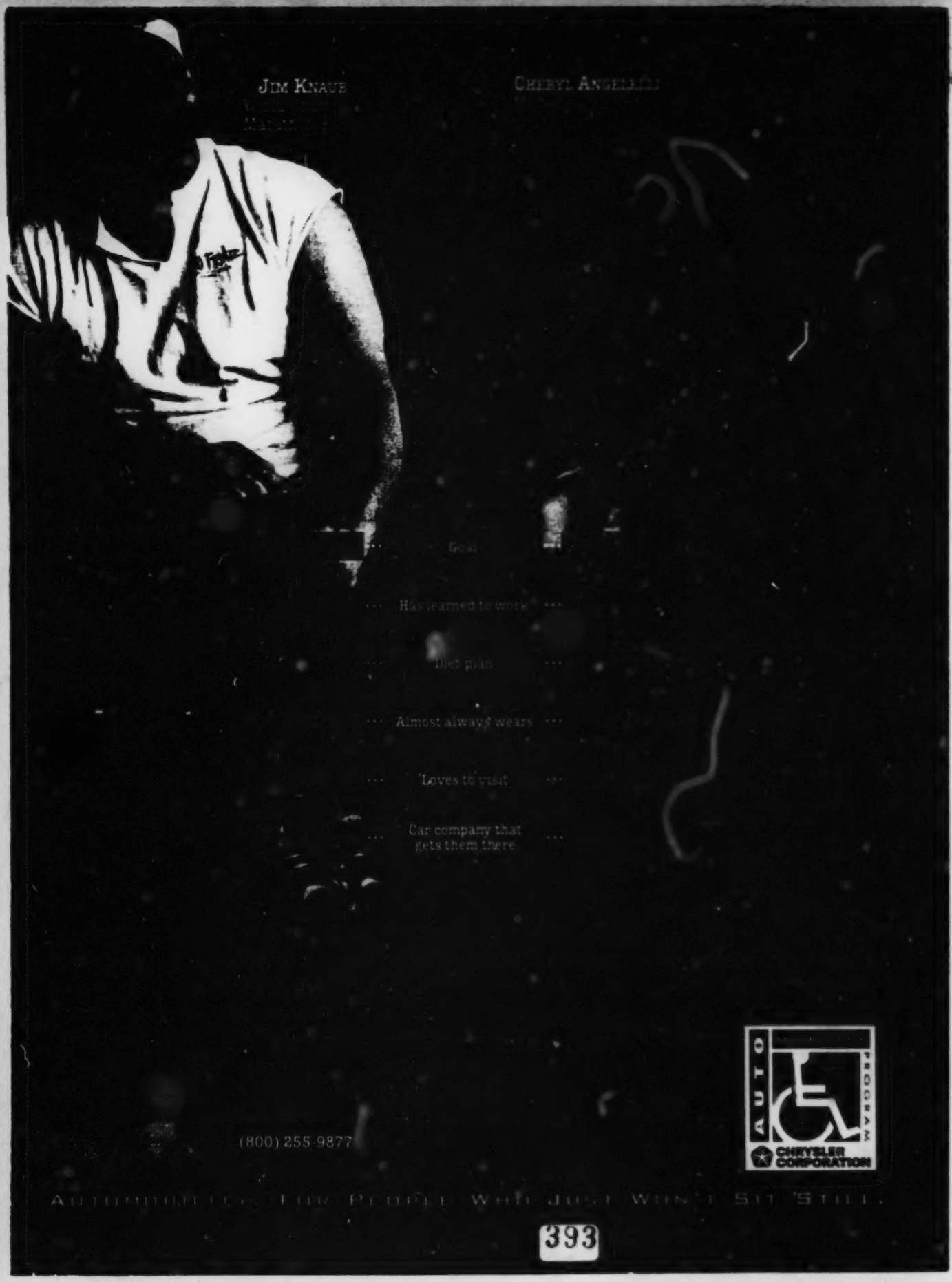
I play with Andy. We play "Roll the Ball." I roll the ball to Andy, but he throws it back to me. We play football, too.

I draw with Andrew. We draw nicely in the lines. Andy just learned how to do it.

I love my brother more than going to Disney World. **EP**

Timothy Sterry, 7, lives with his mother, Leslie, and his brothers, Chris, 9, and Andy, now 6, in New Milford, Connecticut. Timothy, a first grader at Northville Elementary School in New Milford, is an accomplished BMX bicycle racer; he has won more than 30 trophies and is ranked number two nationally in his age division and class. Andrew, who has Down syndrome, also attends Northville Elementary School, where he is included in a morning kindergarten class.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.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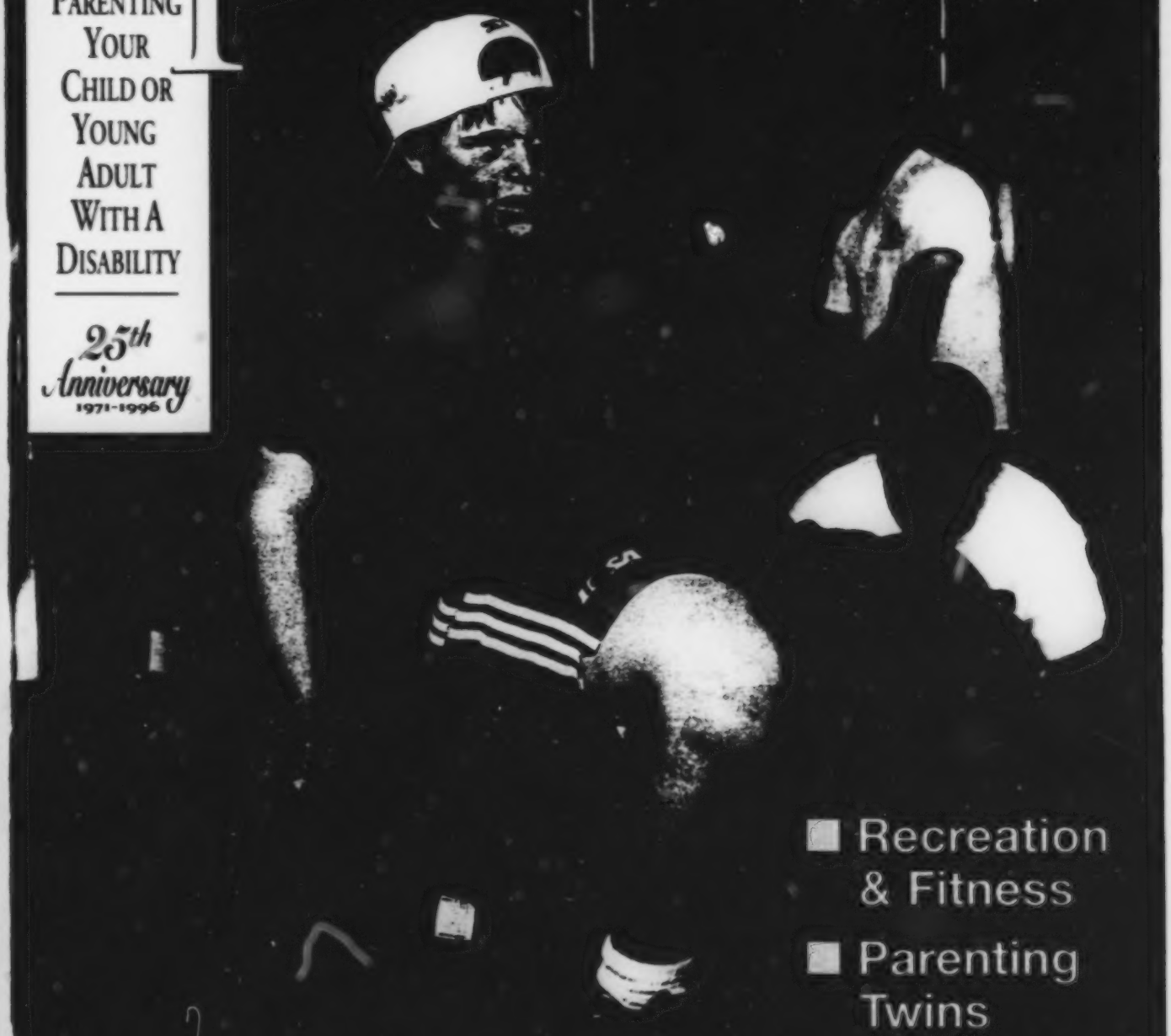

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-Parenting Your Child or Young Adult With a Disability

Since1971

The Magazine for Families and Professionals

MAY 1996 VOL. 26, ISSUE 5

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Cover: Jonathan Derr, 17, works out at the North Shore Jewish Community Center in Marblehead, Massachusetts. Jonathan, who has Down syndrome, is an enthusiastic athlete who uses weight training to improve his skills and be more competitive in his favorite sports: basketball, baseball and golf.

At Swampscott High School, where he is in the tenth grade, Jonathan manages his school's basketball and baseball teams. "Although he doesn't play on the court, he participates," says Jonathan's mother, Jo Ann Simons. For more on Jonathan's athletic activities, see "A Well-Rounded Athlete," page 31.

Jonathan lives in Swampscott, Massachusetts, with his sister, Emily, 12, and his parents, Jo Ann Simons and Chet Derr. Photo: Stuart Garfield

Special thanks to the North Shore Jewish Community Center for their help in arranging this photo.

BPA

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EDITOR'S DESK

Recreation and Fitness

Sports, fitness, recreation! Not so many years ago, these terms would have come up only rarely in discussing the lives of children and adults with disabilities.

STANLEY D. KLEIN, PH.D.

Prevailing opinion once held that individuals with disabilities needed therapy—not recreation. Many parents and professionals agreed. But as this issue's cover and several articles illustrate, recreation and fitness are becoming increasingly important parts of the lives of children and young adults with disabilities, something that is true for many other Americans as well. These days, children and young adults with disabilities have many wonderful opportunities to participate in sports, recreation and leisure activities—in both separate and integrated settings. Many of these activities will become lifelong pastimes that will continue to enrich their everyday lives.

Winning athletes are heroes and role models to many young Americans, including children with disabilities. But parents of children with disabilities also worry about providing their children with role models who, themselves, have disabilities. This issue's *Role Model*, Mike Dempsey, a world-class table tennis player, speaks eloquently about his first coach, John Gray, one of the first adults with a disability Mike had ever met: "John's disability was similar to my own, and seeing what he could do opened up possibilities I hadn't really thought about before..."

This summer, Mike Dempsey will be competing in the 1996 Paralympics in Atlanta, Georgia, along with more than 3,500 other athletes with disabilities. A trip to the 1996 Paralympic Games could be a fun family vacation. And it could be much more—a chance for children with disabilities to see a world of possibilities opened up to them. For more information, see "Destination Atlanta."

Parenting

This issue offers a special section on parenting twins (and in one case, quadruplets). We appreciate the wonderful photographs and stories readers submitted.

Another story in this issue highlights the difference one determined parent can make. As I reported briefly in April, Catherine Evans' battle with a major health insurance company has resulted in a legal victory for her three children, all of whom rely on a special formula to provide them with the essential nutrients they are unable to obtain through a normal diet. As writer John Caher reports in "Perseverance Pays Off," the judge's decision in the *Evans* case may also provide a blueprint for success for families fighting similar legal battles for coverage.

On the net

As we mentioned briefly in our last issue, we are beginning efforts to reach even more parents though the Internet and World Wide Web. See "Virtual Community" for more information; future issues will provide further updates. We are eager for suggestions about the kinds of information you would like to find at our site on the Internet.

25th anniversary celebration

Our Silver Anniversary celebration will be held at Disneyland in Anaheim, California, October 17–20, 1996. We hope to meet many readers and their families at this exciting occasion. The event will include fun activities for all family members, along with educational conferences and product and services exhibits. For details, see page 45.

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LETTERS

Formula Costs

The article "Fighting for Haley's Life" (February 1996) told the story of parents battling their insurance company for coverage of their child's life-sustaining but very expensive formula. But the article didn't ask one important question: Why does the formula cost nearly $20,000 a year? This is outrageous!

I am sick of hearing the old line about the cost of research. Let's face it—the company producing the formula knows they have an essential commodity and can charge what they like. Since our child was born 16 months ago, I have seen enough ridiculous medical costs to be thoroughly disgusted with many laboratories and manufacturers of medicines and peripheral items. The blame does not always belong with insurance companies.

C.W., Louisiana

Why Was Your Baby Born Early?

I was extremely grateful for the article "So... Why Was *Your* Baby Born Early?" (March 1996), in which Teresa Wolding wrote of her resentment at public education efforts linking premature births with mothers' smoking, drinking or drug use. It is a very important problem, one I once tried unsuccessfully to address.

My son, Reese, was born in 1992, three months premature. He now has severe disabilities. Shortly after his birth, I attended a women's health conference where many of the exhibits stressed the importance of prenatal care. I was appalled by the business-sized card the March of Dimes handed out to every attendee. Except for the caption, it was very similar to the public service announcement reproduced in Wolding's article. Under the same two sets of footprints—one tiny, one "normal-sized"—the caption read, "Guess which mother did not receive prenatal care?"

I immediately went home and wrote to the president of the California chapter of the March of Dimes. I explained that this message was misdirected, terribly upsetting and extremely judgmental. I said that my son was born early *despite* the fact that I had received excellent prenatal care and had never used drugs, alcohol or cigarettes. I received no response.

Families shouldn't be harassed about what they did or did not do to cause their child's disability. It's hard enough for parents to come to terms with what life has handed them and, as professionals always advise, to stop blaming themselves.

My sincere thanks to Teresa Wolding, to EXCEPTIONAL PARENT (as always) and to the March of Dimes for addressing this important problem and making some long-overdue changes in their public service advertisements. Fortunately, people's view of children with special needs are changing, and parental advocacy is the main reason disrespect is no longer tolerated. We still have a long way to go, but there are a lot more of us now.

M.E., California

The "Sandwich Generation"

I have subscribed to your magazine for five years and eagerly await its arrival each month. I was most pleased that your December 1995 issue was devoted to grandparents and the important role they play in a child's life.

However, a very important issue was not covered. My husband and I are the grandparents of a beautiful six-year-old girl named Jaimie. She was born with spina bifida, hydro-

continued on page 6

EXCEPTIONAL PARENT
The Magazine for Families and Professionals

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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Circle #155

LETTERS

continued from page 4

cephalus and club feet. She has since been diagnosed with ADD. She has lived with us since she was released from the NICU. We received full custody of her when she was two. Many grandparents are raising their children's children, some of whom who have disabilities.

I've heard us called the "sandwich generation." We are the filling—the best part! In fighting for medical and educational services for our grandchildren, we enter a world that we never expected to encounter, especially at our age. Some of us become involved in the disability network, locally and legislatively. We do what we do willingly—without much support, but with much love. These children keep us young and involved. We have been sent these special angels for a reason, and we have been handed joy untold.

Thank you for the information you provide each month to help us fight the good fight.

D.S., Michigan

More on Homeschooling

This letter is in response to K.S. ("Homeschooling," February 1996), who wrote that she was canceling her subscription because EXCEPTIONAL PARENT "promote[s] a system of education that does not work for [her] child."

K.S., it can be so easy to think our way is the best way, and it usually is—for us. But it may not be the best way for someone else. In my experience, different things have been best for my child and family at different times.

First we did intensive home therapy.

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Write to: *Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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Then we sent our daughter to public school—a super program that provided far more than I could give her at home. When we moved, she ended up in a mediocre public school setting, so we started homeschooling again. After about a year and a half, I put her back in school. Unfortunately, her current school doesn't seem to know what to do with her, so I am thinking of taking her out again, or at least moving her to another school.

The point of this letter is not to tell my story; it is to say that throughout all these changes in my life, I have kept up my EXCEPTIONAL PARENT subscription. There are parts of the magazine I have always liked—such as *Search* and *Respond*—and some things I didn't like, most of which seem to be discontinued eventually. But I've always found the magazine helpful or at least interesting, even if it didn't speak exactly to my situation at any specific time. It would be worthwhile if readers who are homeschooling could write about their experiences, just as it has been helpful when people who choose other educational settings write of their experiences.

It is easy to become defensive when doing something different (such as homeschooling), or just having a child who is different by virtue of his or her special needs. I found myself in defensive mode today when trying to get a referral to a specialist, but I know these feelings really aren't helpful.

B.N., California

■ I homeschool my son who has disabilities, and I would be lost without EXCEPTIONAL PARENT. Thanks for giving information on how to contact NATHHAN, the National Challenged Homeschoolers Associated Network, in your editor's note. Keep up the good work.

J.W., New York

■ I agree with K.S. that EXCEPTIONAL PARENT should include information on the homeschooling option. However, I also agree with the editor's note following her letter that the magazine "is dedicated to recognizing and supporting the expertise of parents" in caring for their children.

I plan to homeschool my daughter. Religious concerns are only a part of the reason. I read *NATHHAN News* and, while I suspect I don't agree with all their Christian beliefs, I do hold to Bible teachings. NATHHAN is a good resource for general information about homeschooling. Their Christian ethics are a bonus. Yet I still feel I will always benefit from the information

continued on page 8

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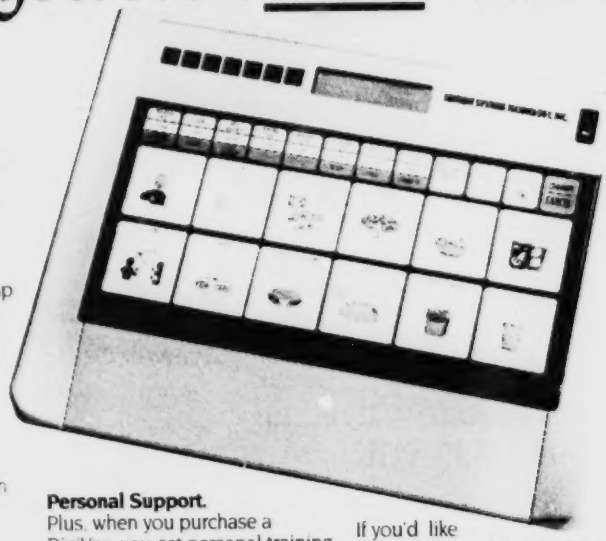

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Circle #16

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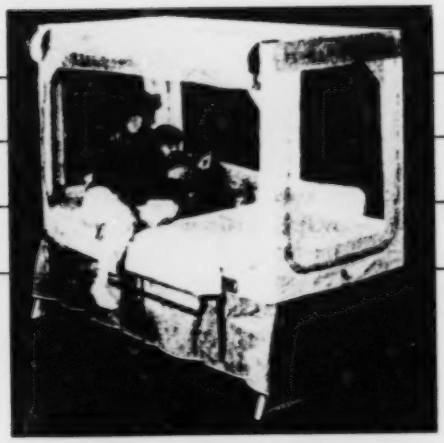

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Circle #40

continued from page 7

and ideas in EXCEPTIONAL PARENT. One does not exclude the other.

As for ending her subscription to EXCEPTIONAL PARENT, K.S. may be "cutting off her nose to spite her face." For her child's sake and hers, I hope she reconsiders. I can't imagine not having EXCEPTIONAL PARENT in my home! In fact, I wish someone had told me about this magazine the day my baby was born. It's invaluable.

D.G., South Dakota

Exceptional Grandparents

I was moved and heartened by the stories on grandparents in the December 1995 issue. My husband and I are doubly blessed with two wonderful pairs of grandparents for our children. These four "exceptional grandparents" are models of love, acceptance, hope and support for our son, Benjamin, and for all their other grandchildren. My own grandmother, who recently passed away, was also an exceptional *great*-grandmother. Her tender love for Ben is one of many special gifts from her I will always carry in my heart.

In the photo, Benjamin, 18 months, enjoys breakfast with his grandmother, Gabrielle Von Fremd (left) and great-grandmother, Mrs. Charles Fremd (right). Ben, now 4, has ring chromosome 18, developmental delays and a hearing impairment, but all who know Ben know that this is not what makes him "special"!

Katherine Murphy, Rhode Island

Thanks!

We have been subscribing to your magazine for the last six years and it has been a great help to us, not only for the great articles, but also for the advertisements of products that can help our child.

Our nine-year-old son has cerebral palsy. Thanks to EXCEPTIONAL PARENT, we were able to find the perfect wheelchair. We have also purchased many other advertised items for our son. Thank you for your help.

G.D.O., Guadalajara, Mexico

■ I am the grandmother of a five-year-old boy with a severe seizure disorder, and I thoroughly love reading EXCEPTIONAL PARENT each and every month. As soon as it arrives, I can't wait to sit down and read it from cover to cover. I have spent many hours laughing, crying and enjoying this wonderful magazine. And as soon as I'm done, I pass it on to my daughter, and she reads it, too.

H.A., Illinois

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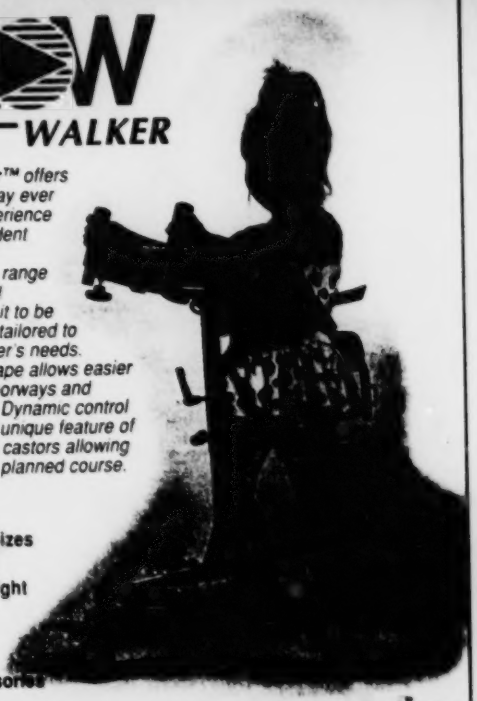
ARROW WALKER



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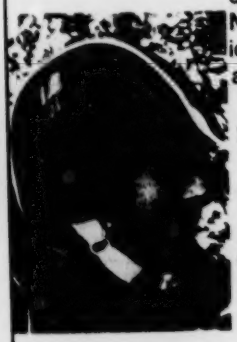

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Circle #271

SEARCH

MMR Vaccine in Utero

As part of my participation in a dental assistant training program, I was required to receive a measles, mumps and rubella (MMR) vaccine. Unbeknownst to me, I was one week pregnant. My son, Joshua, now 17 months old, has cerebral palsy, microcephaly, deafness, seizures and other disabilities.

I have found one other family with a similar child and am interested in finding others. Parents of children exposed to the MMR vaccine in utero can work together to initiate some changes. Our efforts may prevent other infants and families from suffering similar injuries. I've always believed Joshua was given to me for a reason; perhaps this is the reason.

L.R., Virginia

EDITOR'S NOTE: The National Vaccine Information Center (NVIC, 512 W. Maple Ave., #206, Vienna VA 22180; 800/909-7468; 703/938-5768, fax; kunvic@aol.com, e-mail) is interested in hearing from you and others dealing with ill effects of vaccine reactions.

Metabolic Disorder?

Our still-undiagnosed daughter, Maureen, is now 18 years old. She was normal and alert when born, two weeks after her due date. She received only breast milk until the age of five months. A day after her first bottle of milk, she had a 35-minute tonic-clonic seizure. Again breast-fed only, she remained seizure-free until 10 months, about the time we introduced solid food. At that point, her seizures returned and persisted; however, her development remained normal.

I stopped breast-feeding Maureen when she was about two years old. About six months later, we noticed language delays. By age five, she seldom spoke. IQ tests showed steadily deteriorating scores, but CAT scans and blood work remained normal, except for a slight vitamin D deficiency and elevated folic acid.

Maureen has had extreme, paradoxical reactions to most drugs, as well as other substances such as vitamin D and magnesium. Because she cannot tolerate therapeutic drug levels, her seizures have always been incompletely controlled. For years, she chose a diet high in eggs and dairy products—often eating half a pound of cheese for a snack and drinking several quarts of milk a day.

At age 10, she was placed on a total elimination diet. Within 24 hours, she became extremely verbal. All elements except dairy were successfully reintroduced into her diet. During one hospitalization, she was given two pills with lactose as an inert ingredient; within hours, she became completely non-verbal. Her vocabulary and sentence structure are now excellent, but cognitively, she remains very limited.

Currently, she seeks a high-fat, mayonnaise-laden diet, craves bologna and refuses fruits, juices and vegetables. Neurologists feel her disorder is metabolic but cannot identify it. We do not know whether she cannot metabolize a specific protein, or whether her own system lacks a substance that she may have received in breast milk. Can anyone shed some light on these questions?

R.D. & J.D., Maryland

Pierre Robin Syndrome

Our 11-year-old son, Nathan, was born with Pierre Robin syndrome, a variation of the typical cleft palate that includes a small, underdeveloped lower jaw (retrognathia or micrognathia) and a falling of the tongue into the back of the mouth (glossoptosis). In many children, Pierre Robin syndrome occurs as a feature of another diagnosable condition such as Stickler syndrome or trisomy 18.

Some infants with Pierre Robin syndrome have problems with tongue placement partially obstructing breathing. This was the case with

continued on page 12

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Apple

continued from page 11

Nathan, who needed a tracheostomy that was removed after nine months. Nathan has had three surgeries to correct a high arched palate; however, these surgeries were not completely successful. He has a thick tongue and a speech impediment. He also has developmental and motor delays.

I would like to hear from other parents of children with Pierre Robin syndrome. There seems to be little published information on this syndrome, probably because the experts can't agree on the condition.

T.K., Colorado

Dystonia

My two-year-old daughter was originally diagnosed with cerebral palsy (spastic quadriplegia) at eight months of age. However, she was recently rediagnosed with non-progressive dystonia, a rare muscle tone disorder. This new diagnosis came after a second MRI scan showed no sign of brain damage. Doctors have been experimenting with various drugs for this muscle tone disorder. My daughter is currently taking a medication called Sinemet. I would like to talk with other parents or professionals who have had experience with this diagnosis.

D.M., Illinois

EDITOR'S NOTE: The Dystonia Medical Research Foundation (DMRF) can provide information on this condition and can put you in touch with other parents. Contact DMRF, One E. Wacker Dr., Ste. 2230, Chicago, IL 60601-1905; (312) 755-0198; (312) 803-0138, fax. (Canadian readers can contact DMRF at 116-230 Heath St. W, Toronto, ON M5P 1N8; 800/361-8061; 416/487-8326, fax). Both American and Canadian branches of DMRF can be reached by Internet e-mail (dsytfdtn@aol.com) or on the World Wide Web (http://www.iii.net/biz/dystonia.html).

Down Syndrome and Ketogenic Diet

Our six-year-old son, Kyle, has Down syndrome and a seizure disorder. He has myoclonic seizures. Despite trying every known anticonvulsant medication, we've gotten Kyle's seizures under control only a few times, and only briefly each time.

We have also tried the ketogenic diet but had to discontinue it before it had a chance to work. We were using whipping cream for Kyle's fat intake. Unfortunately, he aspirated it and wound up in the intensive care unit with pneumonia. We are considering trying the diet again.

continued on page 14

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

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For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812; (800) 999-NORD; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 RESOURCE Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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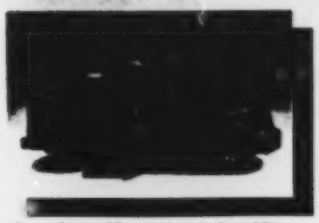
B R A U N



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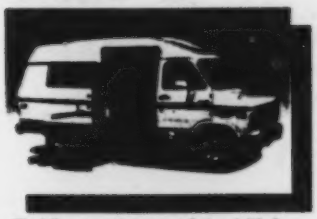

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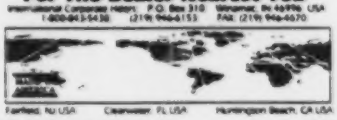

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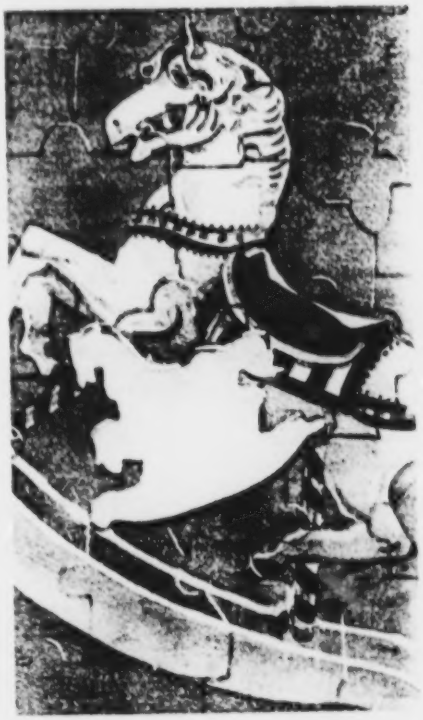

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Circle #221

continued from page 12

but this time using oil instead of whipping cream. We would like to talk with any parent who has tried the diet—successfully or not—with a child who cannot be reasoned with and who does not eat well.

P.S., Michigan

Valproate Acid Syndrome

My daughter was recently diagnosed with valproate acid syndrome, a condition caused by fetal exposure to valproic acid (Dalpro, Depakene, Depakote, Divalproex, Epival, myproic acid) during the first three months of pregnancy.

I am fortunate that my child does not seem to be as severely affected as some of the case histories I have studied. Most of her problems deal with speech; she seems to understand about as much as other children her age, but her expressive language is delayed. She may also have a shorter-than-average attention span.

She has also had several other medical problems that may be related to the syndrome, including frequent ear infections and blocked tear ducts. The circumference of her head is smaller than normal, and she is also small for her age.

I have received some information on valproate acid syndrome, but nobody can give me a long-term prognosis for my daughter. In fact, I've found no medical professionals who have actually seen this syndrome. I need to find other families.

N.R., Montana

EDITOR'S NOTE: The Association of Birth Defect Children (ABDC, 827 Irma Ave., Orlando, FL 32803; 800/313-2232, 24-hour registry line; 407/245-7035, voice/fax) can provide information on this condition and can put you in touch with other parents. ABDC maintains a registry of more than 3,000 cases of non-genetic birth defects, particularly those thought to be associated with exposure to environmental toxins.

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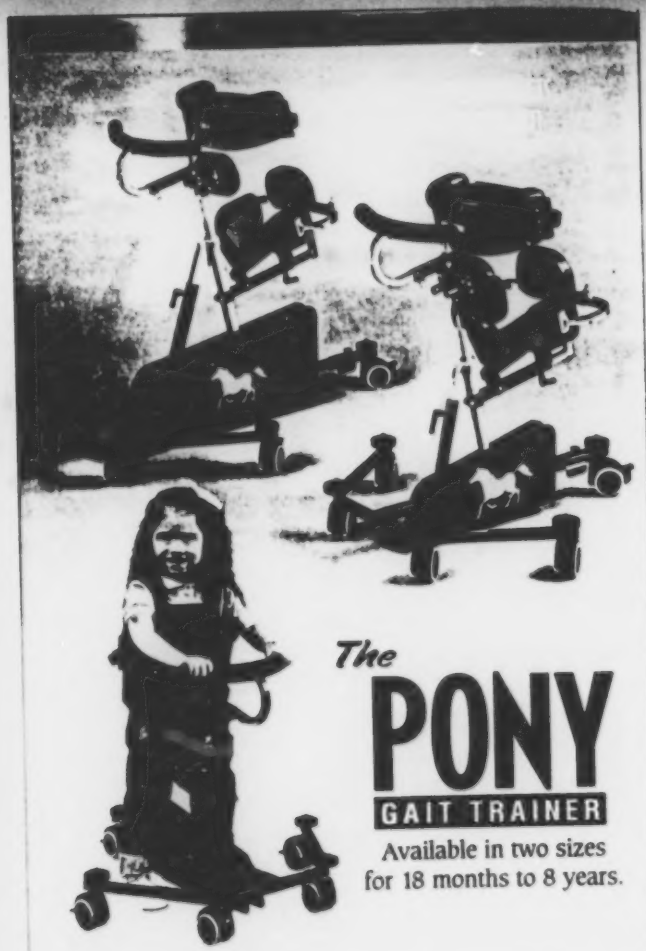

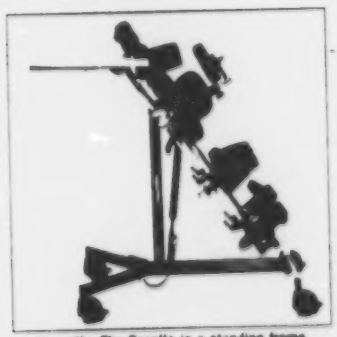
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RESPOND

Biting Problem

C.H. (November 1995) is the mother of 18-month-old Ryan, who has brain stem hypoplasia, myoclonic seizures, mild cerebral palsy and profound mental retardation. Ryan also has a very strong bite reflex and a tendency to put his right hand into his mouth. Ryan can't pull his fingers out until the reflex is completed; by that time, his fingers are bleeding. C.H. wanted to find a way to keep Ryan from biting his fingers that would not involve restricting his arm movement.

Our son, Michael, now 9, has quadriplegic cerebral palsy as the result of a prenatal stroke. He has very little control of his arms and hands and, like your son, tends to put his hand in his mouth and bite.

Several years ago, Michael's occupational therapist suggested an arm splint as a potential solution. The splint kept Michael from biting himself, but it also kept him from mouthing his hand; and this made him extremely frustrated.

I finally thought of using a tall plastic drinking cup. I slip the cup over his hand and put a large white sock over the cup to keep it in place. Now Michael can bite and chew the cup without hurting himself. We just have to watch that he doesn't dislodge it. For extra security, we sometimes pin the sock to the sleeve of his shirt. To keep Michael's hand from getting sweaty, my husband drilled several small holes in the cup.

This invention has dramatically reduced Michael's self-inflicted injuries. When asked if he wants his "biter," he squeals and grins with a knowing "yes!" Michael is fully aware of his ability to hurt himself. If the cup comes partially off, he uses a special vocalization to let us know it needs to be replaced.

Over the last several years, Michael's need for his biter has decreased. Behavior modification at school has completely eliminated the need for his biter in that setting. And at home, he only needs it when he watches videos by himself. If anyone has any other inventive ideas, we would be anxious to hear them, too.

V.V. & R.V., Nebraska

Leg Braces and Ripped Clothing

M.R. (December 1995) has a six-year-old daughter, Maria, with spina bifida. Maria constantly rips her clothing when the fabric gets caught between her braces and the walker. Maria is very fashion-conscious and likes to dress up for school; however, most of her nice clothing now has rips and tears. M.R. was seeking solutions.

I am a physical therapist who has dealt with a similar situation. I work with a seven-year-old child named Sadie, who also has spina bifida. A few years ago, Sadie was dealing with the same problem as Maria. Sadie's parents, the orthotist (brace specialist) and I came up

continued on page 20

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Circle #210

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is the magazine for parents and professionals involved in the care and development of children and young adults with special needs including:

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Perceptual Disabilities
Hearing Impairments
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PROVIDE practical guidance and support for parents, educators and professionals caring for children and young adults with disabilities and special health care needs.

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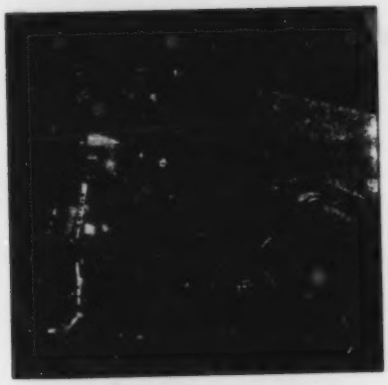
Circle #68



Seven-year-old Sadie shows off her foam-padded leg braces and walker. The foam covering prevents fabric rips and tears that can occur when clothing gets caught between the two surfaces. "Although we've had our share of problems dealing with Sadie's disability," writes her mother in a letter accompanying the photo, "it's the little things like ripped clothing that can be the most frustrating and annoying. We're grateful to have found many people who have helped us come up with solutions."

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with a very successful solution.

The orthotist covered the cable system and hip joints of the RGO's with a layer of one-eighth-inch-thick Pelite foam, a thermoplastic (heatable, moldable, high-density) material often used in lining orthotics or prosthetic inserts. The foam was solidly secured, except over the hip joints, where it could be partially folded back to provide easier access to the locking mechanism. We also wrapped dense foam around the bar on Sadie's walker that made contact with her braces as she walked. To secure the foam on the walker, we used a layer of strong duct tape.

A.W., Pennsylvania

Undiagnosed

R.W. (February 1996) has a one-year-old son, Clay, who was born with several anomalies, including a sacral dimple (a small indentation at the tailbone), bilateral preauricular pits (depressions just in front of each ear) and microcephaly (a small head for his age). Clay was also hospitalized for a severe seizure, but tests and a chromosomal study have turned up no diagnosable disorder. R.W. wanted to know how other parents go about finding answers for their undiagnosed children.

I am the parent of two undiagnosed daughters—Brittany, who will be five in October, and Jessie, who will be two in May. Our own *Search* letter ("Undiagnosed") appeared in the August 1995 issue.

My daughters were born with heart defects, low birth weight and a sacral dimple above their tailbones. They both have feeding problems, are very small for their age and have microcephaly. Results of chromosomal studies have been normal.

Although it took two years to find

continued on page 22

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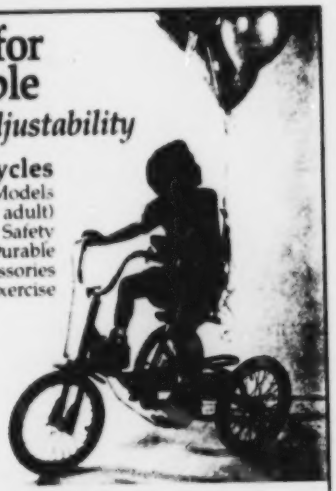

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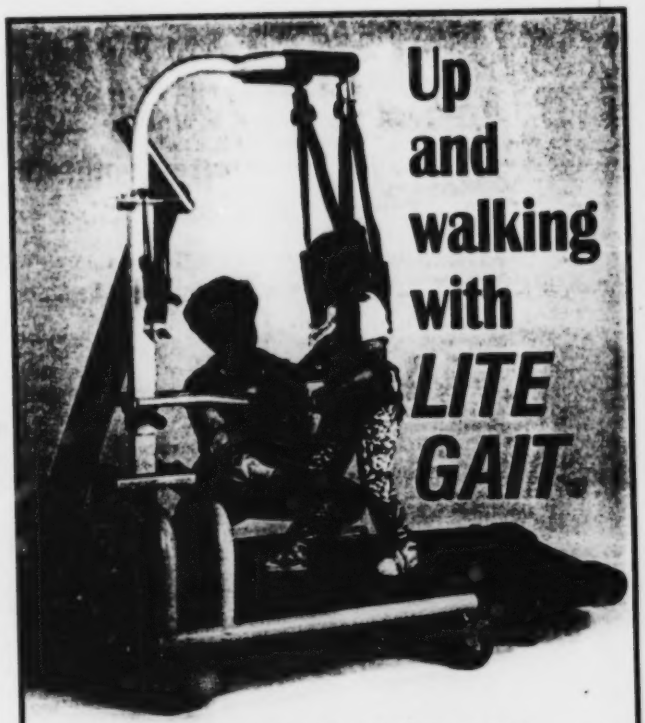

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Circle #13

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a doctor who would listen to me, I eventually had MRIs done on my daughters' spines. It turned out that the sacral dimple was the only outer manifestation of a tethered spinal cord, a condition that could have resulted in serious medical complications without surgery. Have you had an MRI done on your son's spine? If not, I suggest that you bring him to a neurosurgeon and have one done as soon as possible.

J.M., Ontario, Canada

Scoliosis and Failure to Thrive

M.J. and D.J. have a daughter, Hannah, who has Aicardi syndrome, a rare condition in which the corpus callosum (the band of fibers connecting the two hemispheres of the brain) fails to develop. Hannah eats very little, and her body does not seem to get the nourishment it should from the food she eats. Hannah also has scoliosis and cries constantly when placed in her back brace. M.J. and D.J. were hoping other parents could share their experiences in dealing with similar problems.

I cannot address your daughter's eating difficulty, but I can share my experience with scoliosis. My daughter, Melissa, was born with club feet, scoliosis, high arched palate, loose joints and low muscle tone. She has worn a back brace since the age of 17 months.

Here are a few suggestions for making your daughter's brace more bearable: 1) Have her wear a *boy's* T-shirt under the brace. 2) Ask your doctor for adhesive bandages and place them over any sores. These bandages are great and you can leave them on for four to seven days. 3) Line the brace with foam to cushion it. This worked wonders for my daughter. 4) Ask if there is another type of brace you could try. Our daughter once tried a fairly new type of back brace that looked something like a sports leg brace. It was made out of wetsuit-like material.

Because our daughter has a connective tissue disorder, her curve got progressively worse, even with constant brace wear. By last year, her curve was more than 90 degrees. Finally, she had surgery to partially fuse her spine. This was a last resort, but our lives have never been better. Her curve has been corrected to 27 degrees, and Melissa no longer complains about back pain or about her brace. I know surgery isn't always the best option, but in severe cases it may be necessary. Good luck!

D.B., Illinois

Caring for an Adult Sibling

K.W. (December 1995) has a 54-year-old sister, Helen Marie, who has mental retardation. Helen Marie now lives with her mother in Chicago but will come to live with K.W. and her husband in Atlanta when their mother dies. K.W. was looking for suggestions and hints on making Helen Marie's transition a smooth one.

Your goal should be to build relationship bridges for Helen Marie now, so that when she comes to live with you, she won't be as lonely or sad. First, contact a social worker or the recreation director at your local branch of The Arc and request a pen pal. Some of their clients may be willing to send postcards and exchange photos with Helen Marie while she is still in Chicago. Then, when she moves to Atlanta, she will already have friends in the area. You could also begin volunteering at Arc events, so you and your husband can establish relationships with the agency and its clients beforehand.

Since you describe Helen Marie as a "big help" to your mother, she might also be a good companion or friend to an elderly or shut-in person. Ask around at your church, synagogue or local senior citizen recreation center. If Helen Marie comes to visit you before her eventual move, you could even introduce her to her potential "buddies."

M.W., New Jersey

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Circle #157

Scan Time

by Ray Hatcher

It's scan time again, the quarterly event that snaps you back to the reality that your child has a life-threatening disease for which there is no guaranteed cure. But you deal with it. Not because you have nerves of steel or a cold heart, but because you have to, you need to, you want to. Because you know it is better to live with the fear of losing your child than to live with the sorrow of his death.

Scan time makes your mind race wildly. You dream of what life would be like if your family had been spared this cruel twist of fate. The "what ifs" make you temporarily forget the here and now—which is good sometimes, especially when it's scan time.

Matthew, 4, and his sister, Ashley, 7, sport new T-shirts after a visit to the Hard Rock Cafe in Orlando, Florida in 1993. Matthew and his family visited Disney World through the Make-a-Wish Foundation of America, which fulfills wishes for children with life-threatening illnesses.

A little voice snaps you back to reality. "Not another shot, Daddy? I hate shots!"

You hate shots, too. You especially hated them when you had to give them to your child yourself. They were life-giving shots then, necessary evils to maintain blood counts. Now

Ray and Matthew, 3, check out the sights at Disney MGM Studios in the spring of 1992. Three months later, Matthew was diagnosed with a brain tumor.

the shots are needed only to contrast the blood for clearer pictures during scanning. But to your child, they hurt just the same.

"Daddy, will I always get shots?"

"Unfortunately, son, shots are part of life."

"When I grow up, Daddy, I'm going to make a shot that doesn't hurt."

"I hope you do, son. I hope you do."

Yes, it's scan time again. But you accept it as a part of life. For life without scan time would be a life without your child, and no day-dreaming or "what ifs" could ever fill that void.

So you welcome scan time as a celebration of hope and life. The governor has called and your child has been given a temporary reprieve. Time to learn to read and write. To laugh and cry. And maybe, just maybe, to grow up and invent a shot that doesn't hurt. **EP**

Having completed treatment for a brain tumor, Matthew enjoys the sunshine and wildlife at Bay's Mountain Nature Center in Tennessee.

Ray Hatcher lives with his wife, Holly, and their two children, Ashley, 10, and Matthew, 6, in Midland, Virginia. Ray is a senior consultant with Booz Allen & Hamilton, a management and technology consulting firm. Holly raises and shows Shetland Sheepdogs.

In 1992, at the age of three, Matthew was diagnosed with an ependymoma, a tumor that grows in and obstructs the brain's fourth ventricle (one of four chambers in the brain where cerebrospinal fluid is produced and circulated). Following diagnosis, Matthew underwent two brain surgeries, chemotherapy, radiation therapy and monoclonal antibody treatment. These treatments left Matthew with a severe high-frequency hearing loss and some fine motor difficulties. Regular scans done in the two years since finishing treatment have shown no further tumor growth. Matthew is a first-grader at Grace Miller Elementary School in Bealeton, Virginia, and an active Tiger Cub Scout.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Circle #253

Perseverance Pays Off

Family wins long battle with insurance company

by John Caher

As the mother of three children with special needs, Catherine Evans knows that perseverance is the name of the game, particularly in a battle with an insurance company. Through dogged persistence, Evans recently won the important first round in a battle to require Blue Cross and Blue Shield of the Rochester (New York) Area to pay for the formula her children need to thrive. An unprecedented decision by a New York Supreme Court judge ensured Evans' preliminary victory and may provide a blueprint for success in similar lawsuits.

For years, the Evans children—Randi, 13, Brooke, 12, and Drew, 11—had struggled with a multitude of medical problems: raging infections, nausea, gastroesophageal reflux, muscle spasms, vision loss, memory loss, rashes, chronic esophagitis and lethargy. Seven years of testing at hospitals near their home in Warrensburg, New York and at Boston's Children's Hospital proved fruitless.

Then, in late 1994, when Randi was near death, Dr. Kevin J. Kelly, a pediatric gastroenterologist at Johns Hopkins, came up with at least a partial diagnosis—hypersensitivity to complex proteins. And, just as important, he came up with a treatment program. Dr. Kelly prescribed Neocate One Plus, a formula produced by Scientific Health Supplies of Gaithersburg, Maryland. Neocate One Plus is a predigested amino acid formula that provides the Evans children with the essential nutrients they are unable to obtain through a normal diet due to their inability to digest complex proteins.

Miraculously, after starting on the predigested formula, the condition of the Evans children improved. They began to recover from the constant bouts of illness precipitated by their weakened immune systems, and their mother was able to slowly reintroduce various foods into their diets. All was well, or so the family thought.

Insurance company balks

From there, however, the story took a twist that will sound familiar to many, especially those who read the story of Haley Engleman in the February 1996 issue of EXCEPTIONAL PARENT ("Fighting for Haley's Life"). The Evans' insurance company balked.

(From left) Drew, Randi and Brooke enjoy a visit to Six Flags during the summer of 1995. Catherine Evans explains, "This was the first time Randi and Brooke could comfortably walk around an amusement park. Prior to starting the Neocate formula, Randi and Brooke would become extremely ill and have severe pains throughout their bodies with even mild exertion. Randi was in a stroller most of the time."

The Evans family sought to have their insurance company, Blue Cross and Blue Shield of the Rochester Area, cover the formula's cost. The company, perhaps predictably, cringed at the $600-per-month-per-child cost, claiming that Neocate One Plus is a food supplement and, therefore, not covered by the family's policy.

However, the insurance company offered a few peculiar exceptions to that rule. First, after much pestering by Cathy Evans, the company suggested it would pay for the formula if the children were hospitalized and the substance delivered through a nasogastric (NG) tube. Cathy refused to hospitalize her children to obtain a formula they could simply drink out of a carton and suspects that the insurance company made the offer believing that she would never consent to such a radical and costly approach. Later, when the family had grown increasingly desperate, Blue Cross and Blue Shield offered to pay for the formula for one month, but only if the family signed away any potential rights to further coverage. No way, Cathy told them.

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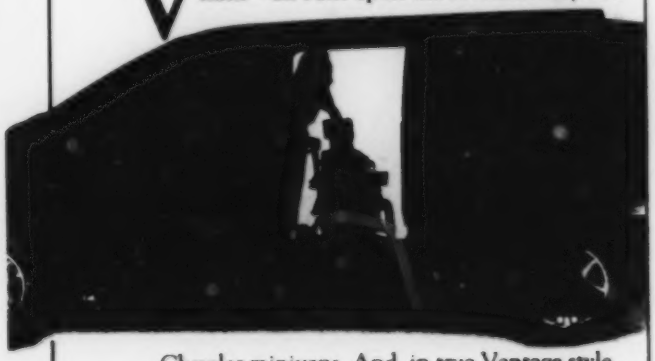

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continued from page 26

Finally, Medicaid agreed to temporarily pick up the tab for formula for the two older children, who have a diagnosed chromosomal disorder, but that put Cathy in the heart-wrenching position of rationing two doses of formula among her three children. In order to help Drew, she had to shortchange Randi and Brooke. Furious, Cathy struck back with both a legal and a public assault.

A powerful ruling

With the help of a lawyer more concerned with righting a wrong than collecting a fee, the Evans family went to the mat with Blue Cross and Blue Shield. Since the Blue Cross and Blue Shield contract clearly does not cover food supplements, the outcome of the case depended on whether the formula would be considered as a supplement or as a drug. On Feb. 15, 1996, attorney Kevin A. Luibrand of the Albany, New York firm of Tobin and Dempf won an important first ruling in the trial court.

Supreme Court Justice Lawrence E. Kahn issued an injunction ordering Blue Cross and Blue Shield to pay for the Evans' formula pending a trial on various issues, including breach of contract. Justice Kahn's decision, reported extensively by the local media and distributed by the Associated Press, found that Neocate One Plus is both a drug and part of an ongoing diagnostic process. This creatively crafted decision provides a decidedly powerful ruling for the Evans family and other families of children with similar needs. The judge based his finding on the courtroom testimony of Dr. Kelly, now at St. Christopher's Hospital in Philadelphia. Justice Kahn found that the purpose of the formula is to allow the children to exist without complex proteins, but with essential nutrients, during a series of diagnostic procedures called "food challenges." Food challenges reintroduce various foods, one at a time, into the children's diet in an attempt to differentiate foods they can tolerate from those they cannot.

"Without Neocate, the lunchbox will remain a minefield because what constitutes a safe diet will never be determined," the judge wrote. "Dr. Kelly does not intend that the Evans children remain on the Neocate formula for a lifetime. His goal [is] to develop a categorically diverse list of foods that the children can tolerate by means of food challenges. Eventually, the children would not utilize Neocate since they would be able to ingest normal foods that comprise a restricted but nutritionally sufficient diet."

Mark A. DeFries, chief executive officer of Scientific Health Supplies, said the imported raw ingredients for the Neocate formula, which, unlike other predigested formulas, is created from scratch and built up (rather than started from a protein base and broken down), are costly. So is the quality control process. The company specializes in formulas, for children with inherited metabolic disorders. Neocate One Plus was first tested about three years ago in a clinical trial supervised by Dr. Kelly and became commercially available in August 1994, shortly before Dr. Kelly prescribed it to the Evans children. A similar infant formula, for children under the age of one, was recently approved by the FDA.

(From left) Randi, Drew and Brooke Evans, Christmas 1995.

"Coercive tactics"

In addition to its legal loss, Blue Cross and Blue Shield took a public relations battering from Justice Kahn, who was particularly critical of the insurance company's tactics, which he described as "coercive." The judge expressed disgust at the way Blue Cross had treated the Evans and accused the company of trying to skirt its contractual obligations by buying off the family in exchange for one month of formula coverage.

"Blue Cross sought to limit its liability and foreclose any future claim for payments for Neocate in exchange for one month of peace for the children," the judge wrote. "This was in direct contravention of the terms of the policy and is, frankly, reminiscent of an old story by Goethe."

Philip Puchalski, a spokesperson for Blue Cross and Blue Shield, said the company maintains its position that the formula is not a covered expense, but said it decided not to appeal the injunction because "there is no reason to put the family through any more." He stressed, however, that the company intends to mount an aggressive fight at trial. "The issue is setting a principle for providing a benefit excluded by contract, which would set a precedent for other cases," Puchalski said.

The case is now slated for a trial before Justice Kahn. Since he has already decided the formula is a covered expense, the primary issue at the trial will be whether Blue Cross and Blue Shield intentionally violated the terms of the contract and, if so, what damages should be paid. In New York, the Supreme Court is the entry level, or trial, court and its decisions are subject to review by two higher tribunals. If both levels of appeal are utilized, the case could continue for another year or two before final resolution.

New legislation

Attorney Luibrand, who took the case on a pro bono basis but might be able to recoup his expenses at trial, said he has been deluged with calls from lawyers who had heard about Justice Kahn's reasoning and were interested

in framing their own arguments along those lines in similar cases. The judge's decision also impressed a couple of New York state legislators, Senator George D. Maziarz of Niagara Falls and Assemblywoman Elizabeth A. Connelly of Staten Island, who immediately proposed legislation that would require insurance companies to pay for formulas like those needed by the Evans children.

Like some other states, New York law requires insurance companies to cover certain formulas needed to treat a handful of specific metabolic disorders. The pending legislation would substantially expand the existing law by requiring insurance companies that provide prescription drug coverage to pay for all formulas or food products ordered by a physician to treat a vast array of medical conditions, including still undiagnosed disorders.

"When a mother is faced with the choice of either rationing a formula her three children need to stay alive and healthy, or going on welfare to pay for the drug, we are faced with the reality that there is a major flaw in our system," said Senator Maziarz.

Catherine Evans' persistence paid off with a major victory in her battle with Blue Cross and Blue Shield of the Rochester Area. "Insurance companies get away with this because people don't have the energy or assets to fight," she says.

Assemblywoman Connelly views such formulas as preventative medicine. "The costs are minimal to the insurance company in relation to some of the disorders that can develop if this special food is not provided, such as mental retardation, seizures and neurological dysfunction," she said.

Meanwhile, the Evans children are thriving while their mom gears up for the next round of legal battles. "Insurance companies get away with this because people don't have the energy or assets to fight," Cathy said. **EP**

John Caher reported on the Evans family and their battle with Blue Cross and Blue Shield of the Rochester Area for the ALBANY TIMES UNION, *where he is a staff writer.*

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Circle #15 425

RECREATION

SPORTS AND FITNESS:

Meaningful Participation

by Naomi Angoff Chedd

Children with disabilities and their parents often face particular difficulties when it comes to sports participation—difficulties finding acceptance in school and community activities, difficulties securing the necessary financial resources for special equipment or aides, and difficulties enlisting the help of people who know how to adapt the activity or environment for successful inclusion.

Adaptations that work

Many early childhood educators believe that inclusion in recreational activities is usually easiest at the preschool and early elementary levels, where noncompetitive activities are the norm. Typical playground games often can be easily adapted for children with differing abilities. "It's fun to change the rules and experiment so everyone can play," says one preschool teacher. "Sometimes, we invent a more exciting game, rather than playing by the same old rules."

But as children get older, inclusion often becomes more challenging. Robin Friedlander, community recreation liaison at the Institute for Community Inclusion at Boston's Children's Hospital explains, "To make inclusion work, you have to demystify the word 'disability.' It conjures up all kinds of ideas, many of them completely inaccurate."

Based on her experience, Friedlander believes that teachers and coaches will be more receptive to inclusion if parents describe a child in terms of his or her strengths and weaknesses—for example, talking about the child with a disability as a kid who has difficulty hitting, kicking or seeing the ball, but who is a terrific runner. This approach can help the coach or instructor view the child as a child, not as a problem.

She recommends that any adaptations made should be made for *all* participants. If a child cannot hit a pitched ball but can hit the ball off a tee, for example, the coach can give every child the option of hitting off a tee. If a child can kick a ball but can't run, the coach can institute an optional "designated runner" rule. If the child with a disability gets stickers for good behavior, the instructor can give everyone stickers for good behavior. Offering adaptations to all children avoids singling out the child with a disability. "You don't necessarily need any special training to adapt activities and sports for kids with disabilities," Friedlander says, "just some imagination and the willingness to make it work."

Participants in summer programs sponsored by the National Sports Center for the Disabled (NSCD) enjoy the Bonfils-Stanton Winter Park Outdoor Center in Winter Park, Colorado, which provides a universally-accessible trail system for hiking, camping and fishing. (For more information, call NSCD at 303/892-5823.) Photo: Jeff Stine.

Participants in the Shepherd Center's annual Adventure Skills Workshop enjoy a number of water- and land-based recreational activities, including water skiing, scuba diving, riflery, a ropes course and gardening. The workshop is designed for individuals with spinal cord injuries and neuromuscular disorders. (For more information, call 404/350-7572 or 404/350-7484.)

Friedlander's sentiments are echoed by John Passorini, an adapted physical education specialist in the Wayland (Massachusetts) Public Schools. Passorini, who works with children of all ages, believes that other children are an often underused resource. "Ask the kids to alter the rules, change the environment or think of ways a particular child can participate," he advises. "Kids are creative in their thinking. They can often come up with better ideas than some of the professionals."

Meaningful participation

Passorini believes that inclusion only works when all participants are included in a functional way, "not just as add-ons or mascots." For this to occur, says Charles Sisung, M.D., director of the Pediatric and Adolescent Program

Creating an Inclusive Setting

"We've been working on inclusion in sports and recreation for four years," says Margaret Kelligher-Gibson, the mother of 10-year-old Matthew and seven-year-old Suzy. Suzy, who has autism and mental retardation, is a happy, well-adjusted child, but it's hard to teach her academic and recreational skills, her mother explains. She usually needs specialized, individualized instruction.

Margaret Kelligher-Gibson participates in an Easter Seal swim program with daughter Suzy, 3.

Margaret and her husband, Bob, get together regularly with other parents of children with similar disabilities, and they've come up with some solutions to provide their children with inclusive sports and recreational opportunities. The group has rented a health club and the Discovery Zone, an indoor playground, for a few hours and invited their children—including all the siblings—to come and play. "It can be difficult for our children just to show up at these places and have a good experience," says Margaret. "Many of them are environmentally sensitive and need lots of help and practice. So we've created an inclusionary setting, since there are many more siblings than children with disabilities." Suzy has also attended a music and movement class where siblings are welcome, too.

Margaret believes that many skills can be taught in a separate setting, and then used successfully in the community. For example, Suzy learned to swim at an Easter Seals swim program before attending a regular swim class with an aide. "It worked," says Margaret. "The other kids and parents were receptive and supportive." Margaret also credits the Massachusetts Department of Mental Retardation (DMR) for providing support and the money to pay for an aide at the community swim program. "I don't know if I would have had the courage without the help of DMR. Families can't do it alone. We need to feel that everybody wants inclusion to work."

at the Rehabilitation Institute of Chicago, the people in charge—in schools, community recreation programs and organized sports—have to believe that fitness is equally important for those with and without disabilities, and they need to convey that message to their staffs. But Sisung also says that parents, kids and instructors have to be realistic. Inclusion can work in many circumstances, but not all.

Although competitive and team sports present the greatest challenges, successful inclusion is possible in some circumstances. For example, Passorini cites one child with spina bifida who became a "serving specialist" on a volleyball team. Clearly, every adaptation does not require major changes, planning or complicated equipment. On the other hand, as Dr. Sisung points out, exclusive programs such as wheelchair sports or the Special Olympics also offer quality recreational opportunities for children and adults with disabilities.

Dr. Sisung continues, "Many kids want to experience competition and mastery, even if they aren't involved in athletics." Board games and electronic games may be able to fulfill these needs. He adds, "Any sport or recreational activity is worthwhile if it's safe and kids feel good about it."

More than a game

Recreational activities and sports play enormous roles in the lives of many children, with and without disabilities. It's often more than the actual mechanics of the sport, or even having a chance to play in every game. Getting involved, being part of a team and contributing in some way to the group's success is what matters most.

Successful adaptations at the elementary and middle school levels won't necessarily work in high school, where sports takes on greater significance for many. But at every level, children with disabilities can participate as long as staff and other participants have a positive attitude and are not afraid to stretch, experiment and blaze new trails. Sometimes it's tough, but when inclusion works, it's exciting and satisfying for children of all abilities. **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT*'s editorial staff.*

A Well-Rounded Athlete

Jonathan Derr, 17, lifts weights and works out regularly at the North Shore Jewish Community Center in Marblehead, Massachusetts. He manages his school's basketball and baseball teams, shoots 102 in golf and plays a mean game of pool. Jonathan also has Down syndrome.

Jonathan's mother, Jo Ann Simons, has worked with her son, the schools and the community to ensure that Jonathan can be involved in sports in a meaningful way. "As manager of his basketball team, Jonathan plans shots at games and works with the team on drills during practices. He doesn't just get dressed for the game. Although he doesn't play on the court, he participates. He does a job that needs doing.

Avid golfer Jonathan Derr, 17, won a bronze medal in the golfing competition at the 1995 Special Olympics World Summer Games in New Haven, Connecticut.

"We all need to look at how our kids can be involved purposefully in sports and recreation," Jo Ann emphasizes. "Families need to find out what interests and motivates their kids and then find ways for them to participate."

Jonathan has also competed in the Special Olympics, another valuable part of his life. "Jonathan met lots of outstanding athletes, including one young man named Sean, whom he admired tremendously," says Jo Ann. "It was irrelevant that Sean had Down syndrome; to Jonathan, he was just a great golfer. On the other hand, Jon got a real thrill that he and many other athletes were being celebrated, and that the celebration included their disabilities."

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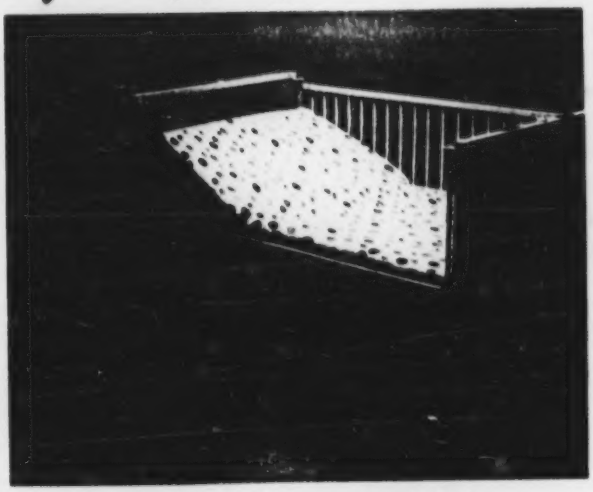

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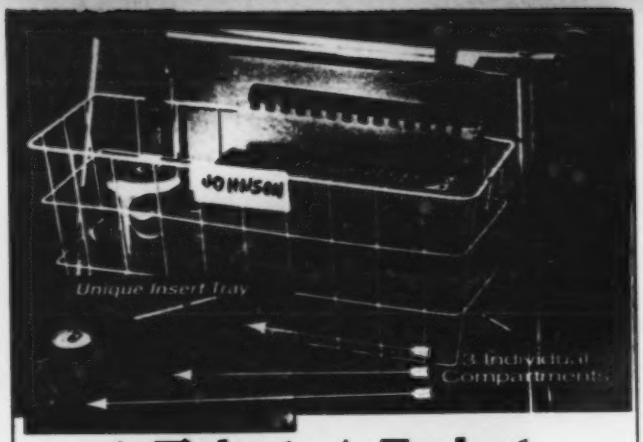

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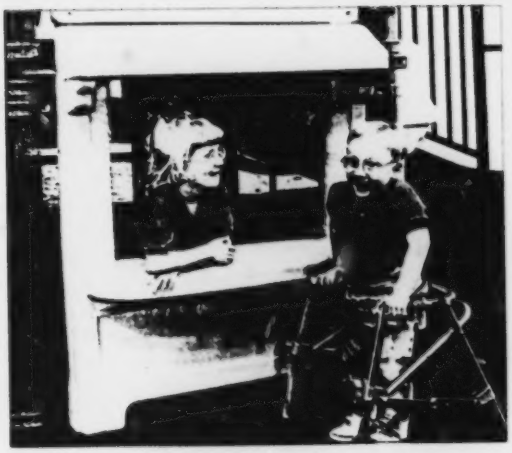
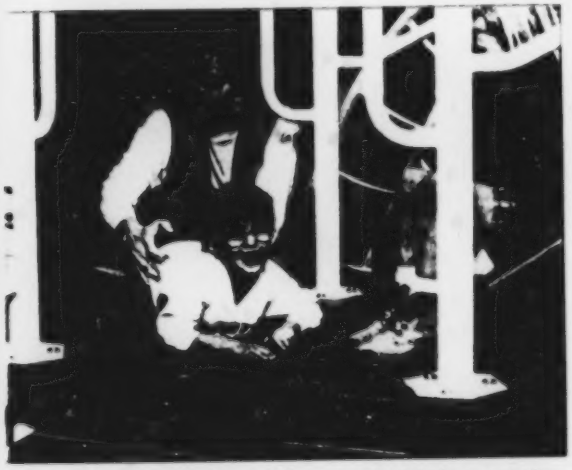
RECREATION

GUIDELINES FOR SAFE, ACCESSIBLE Playgrounds

The Americans with Disabilities Act (ADA) requires that all public accommodations, including recreational areas like playgrounds, be accessible to individuals with disabilities. Expanding on this requirement, the American Society of Testing and Materials (ASTM) has developed accessibility standards for manufacturers of play materials. Of course, safety is just as important as accessibility. Outlined below are guidelines for safe, accessible playgrounds.



Rubber mats and rubber-like surfaces provide playground access to children with wheelchairs, scooters and walkers. Photo courtesy of Little Tikes Commercial Play Systems.



Transfer points allow children in wheelchairs or scooters to climb onto playground equipment more easily. Photo courtesy of Jay Nicholson, The Nicholson Agency on behalf of Miracle Recreation, ©1995.

A safe, accessible route

• *Paths* to playground equipment should be wide enough for a wheelchair or scooter (at least 60 inches).

• *Pathway surfaces* should be made of uniformly sized wood chips, rubber mats, rubber tiles or poured, rubber-like substances. Wheelchairs, scooters and walkers can maneuver easily on such surfaces. The surface material should be thick enough or deep enough to provide adequate shock absorbency, reducing the chance of injury in case of a fall.

Ramps and transfer points

• *Wheelchair ramps* leading onto playground equipment should have rails and raised edges to prevent wheelchairs and scooters from slipping off the sides. ASTM has specific guidelines for the correct slope and length of wheelchair ramps.

• *Transfer points* (raised platforms where a child can get out or be helped out of a wheelchair or scooter to climb onto the equipment) should be fitted with handrails or hand holds at the transfer point so the child can grab on easily and climb safely. There should also be enough room at the transfer point for a wheelchair or scooter to turn around.

Playground equipment

One of the most important parts of going to the playground is getting exercise through fun, physical activity. For children with disabilities, an equally important consideration is that accessible equipment be integrated with non-accessible equipment. Not every piece of play equipment needs to be accessible, but when non-accessible swings, for example, hang alongside accessible ones, it promotes social interaction between children with and without disabilities.

Play equipment should be separated, however, based on age group. Injuries and collisions can be prevented if preschoolers have a play area separate from that for six- to 12-year-old children. Children with disabilities can play in the area that best meets and challenges their abilities.

A safe, accessible playground can include such equipment as overhead rings or bars, bridges, slides, swings and sandboxes.

• *Overhead rings and bars* need to

continued on page 35

Social interaction, supervision and safe, accessible equipment are key elements of a successful playground. Photo courtesy of Playground Environments.

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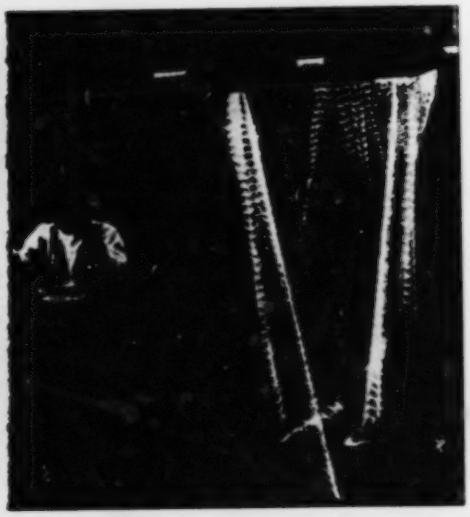
continued from page 34

be low enough so a child can reach them from a wheelchair or scooter.

- *Bridges*, like ramps, need to be wide enough for wheelchairs and scooters and provide rails and hand holds.
- *Accessible slides* should have an accessible means of getting back to the entrance point—such as a path with proper surface material, not sand or dirt.
- *Swings* should provide adequate body support.
- *Sandboxes* can be elevated so children in wheelchairs and scooters can roll up to them.



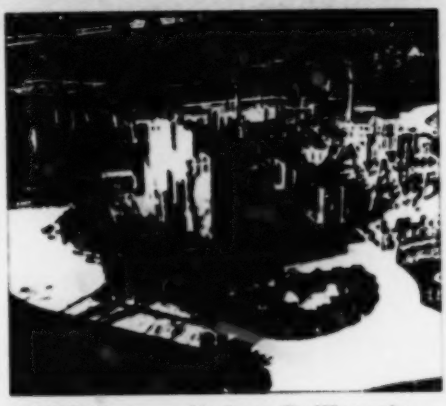
This special sling makes a regular swing accessible while providing proper head and body support. Photo courtesy of Parity.

Manufacturers of playground equipment may offer other accessible play items, such as easy-to-reach hand manipulatives and activity panels with tic-tac-toe, matching, math and spelling games. Some companies also offer special, wheelchair-accessible digging tools for sandbox play.

General safety precautions

- *Fences* with a gate should surround the playground area if it is located near a street or parking lot.
- *Clean, well-maintained play areas*

When a Community Came Together



CAMDEN Playground in Janesville, Wisconsin, may be the largest accessible playground in the United States.

My son, Camden Hookstead, now 14, has mental retardation with autistic behaviors. When Camden was young, I would take him to the local playground for fun and exercise. But, unlike other parents, I could not sit and relax while Camden played. Because the park did not accommodate children with special needs, I constantly had to help my son swing, slide and play in the sand.

One day, my boyfriend, Todd Long, who was studying to be an occupational therapist, suggested that we build a park that would be accessible to children with disabilities. At first I thought he was crazy, but as we talked to people in our community and shared the idea with them, I, too, began to believe in Todd's dream.

First, we created a board to plan and coordinate fundraising. We contacted businesses, schools and disability organizations. The 28-member board, which included attorneys, doctors, teachers, parents, my mother and my sister, began to plan fundraisers. We held auctions, a moonlight ski event, a bowl-a-thon, a beach party, a softball tournament with the fire department, a gourmet dinner event, bake sales, craft sales and cookbook sales—just to name a few. We also applied for grants and solicited donations from local businesses.

Two years of fundraising were well rewarded. We raised nearly $150,000, including a $50,000 donation from Ronald McDonald Children's Charities and a $20,000 donation from the local Harley-Davidson Motorcycle owners group.

We broke ground on September 23, 1992. More than 2,500 volunteers, including members of the National Guard, were on hand to help—we even got the children involved. The city of Janesville, Wisconsin, provided engineers and park staff to help us. Businesses donated supplies like cement, gravel, sand, dirt and grass seed. The telephone company let us use their trucks to dig holes. This was community involvement at its best!

We finished our work on May 23, 1993. We named the new park CAMDEN Playground, after my son, but it also stands for Community Accessible Medium Dealing with Exceptional Needs. The park is as big as three football fields. It is 85 percent accessible to wheelchair and scooter users and 100 percent accessible to children who use walkers. We have accessible swings with seat belts and back and side supports, bars to improve upper body strength, slides, a sandbox, a bucking bronco, a castle and moat, a tree house, an accessible stage and picnic tables. We also designed a maze and have Braille activities for children with visual impairments. In the future, we hope to build accessible swimming pools and basketball courts.

The entire community came together to help build CAMDEN Playground. Here, members of the National Guard put finishing touches on the playground swings.

We donated the playground to the city of Janesville, Wisconsin; the city takes care of all maintenance and upkeep. CAMDEN Playground has won numerous awards and serves as a model for other accessible playgrounds. Attendance at Palmer Park, where CAMDEN is located, has increased by 50,000 people a year since the playground was completed.

Now, my son and all the children in our community have a fun, safe and accessible place to play and call their own. And I can finally relax while Camden plays.

—Sara Knutson
Milton, Wisconsin

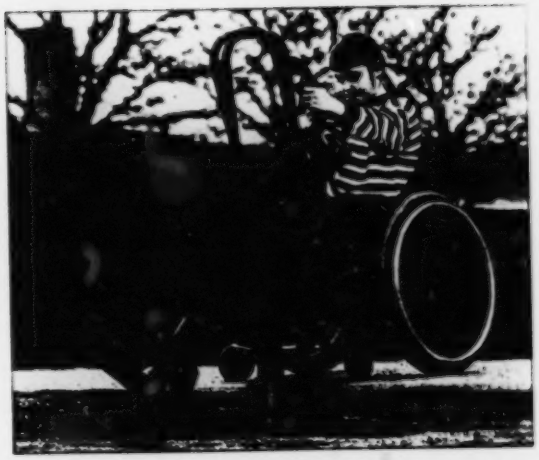
are important for safety. Picking up scattered garbage and debris not only reduces the chance of tripping and injury, but also keeps the playground attractive.

• *Supervision* should always be provided for children during play.

If your playground is not accessible

Parents and communities throughout the country have joined together to raise money and build accessible playgrounds. Involve friends, neighbors, local clubs, organizations and support groups. Ask for ideas and support. Contact manufacturers of playground equipment; they can help you design a playground that follows safety and accessibility regulations; they may also be able to help with fundraising. It can take a lot of work, but the end result will be a fun place where all children can play. **EP**

—Kristen Holmstrand



Unique components, like this sandbox digger, enable children with disabilities to take advantage of playground equipment that might otherwise be inaccessible. Photo courtesy of Nordstrom and Partners on behalf of Gary Van Deusen, Recreation Creations.

Thanks to Donna Thompson, Ph.D., director, Program for Playground Safety, University of Northern Iowa, Cedar Falls, Iowa; Elaine Sherman, CPSI (Certified Playground Safety Inspector), Access Recreation Group, Oak Park, Illinois; and Brian Jenkins and Heather Harris at Little Tikes Commercial Play Systems, Farmington, Missouri, for their contributions to this article.

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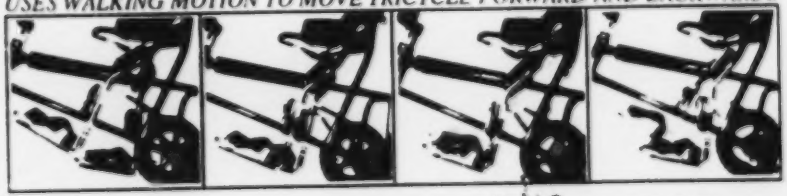

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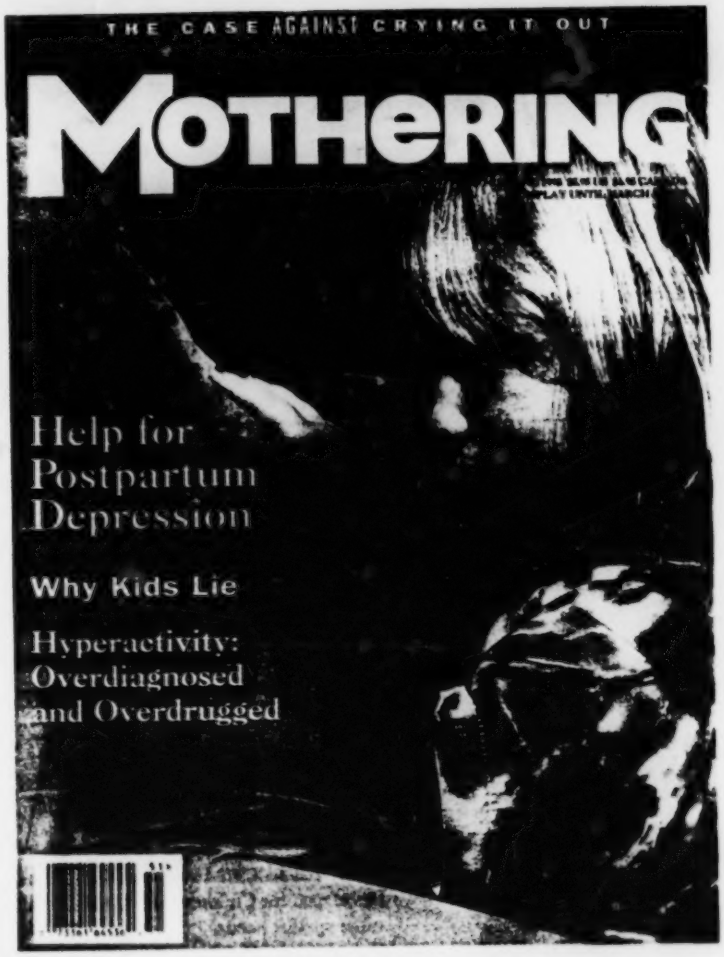

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Circle #293

Mike Dempsey
Turning the tables

Mike Dempsey, 39, a member of the United States Paralympic team, is currently training for the 1996 games in Atlanta, where he will compete in table tennis. Dempsey, who has partial paraplegia, began his Paralympic career in 1972. He won a gold medal at the 1988 Paralympics and a silver medal at the 1992 games. In 1993, Dempsey was inducted into the National Wheelchair Athletic Association Hall of Fame.

Dempsey is one of the owners of Kuschall of America, a wheelchair manufacturing company. He lives in Camarillo, California, with his wife of five years, Shannon, two golden retrievers and three cats. When not working or training, Dempsey enjoys doing "anything to do with the outdoors," especially boating and camping. The following was adapted from an interview between Dempsey and EXCEPTIONAL PARENT *intern Tiffani C. Willis.*

I was born in 1956, in Columbus, Ohio. When I was six months old, doctors discovered a skin tumor on my back. They gave me an injection to stop its growth. However, the roots of the tumor had wrapped around my spinal cord. Although the tumor did not sever my spinal cord completely, it resulted in partial paraplegia. I do have some movement in my legs.

Kids can be creative

When I was a child, most children with disabilities attended special schools. I was lucky to be mainstreamed from the very beginning. I believe mainstreaming is not only good for the child with a disability; it is also good for the other children, who can learn to deal with kids who have differences. I have found that when someone is shy around a person with a disability, it's usually because they have never met someone with a disability before and don't know how to react.

Of course, my school had one or two bullies. But you don't have to have a disability to experience teasing; those kinds of kids aren't too choosy. For the most part, however, my teachers and the other kids were supportive in trying to figure out ways for me to be included. I got involved in as many activities as possible. I played touch football; I had a good arm so I was the quarterback. I also played baseball. I pitched or hit and let someone else run the bases. Kids can be pretty creative.

Mike Dempsey developed partial paraplegia at the age of six months as the result of a spinal cord tumor.

Spirit of competition

I've always been pretty competitive. Some of that probably comes from having to try and make my place within a regular class—that, and having to hold my own with five older sisters. That competitive spirit carried over into sports.

I began playing table tennis during recess at school when I was 12. I won the school's table tennis tournament. Some of the kids I had defeated in the finals complained that I had broken the rules because I touched the table; this was because of the way I sat in my chair and held onto the table during a game. I realized I needed to learn the best way to play this game in a wheelchair.

Several years earlier, my mom had clipped a newspaper article on John Gray, the national wheelchair table tennis champion. John, who had paraplegia as the result of a car accident, lived in my town. So my mother and I called him and asked if he could give me some pointers. He asked me to meet him at the local table tennis club, and that was the start of my athletic career.

continued on page 40

Dempsey (front left) pauses before the start of play at the 1992 Paralympics in Barcelona, Spain, where he won a silver medal in the singles competition.

continued from page 39

Role models

John took me under his wing, becoming my coach and my practice partner. John was one of the first adults with a disability I had ever met. Prior to that time, I hadn't really been around other people with disabilities, except maybe at therapists' offices.

John's disability was similar to my own, and seeing what he could do opened up possibilities I hadn't really thought about before, like driving—not that I was quite ready to drive at 12! I learned a lot from John and, later, other athletes in chairs as I observed the techniques they had developed for dealing with life's challenges.

Competition

At the Paralympics, I compete in wheelchair events against other people in chairs. I went to my first Paralympics in 1972, when I was 15 years old. I think I was the youngest wheelchair athlete ever to win a national championship, and that was at age 13.

Newlyweds Mike and Shannon Dempsey enjoy a 1990 trip to the World Games in the Netherlands.

At my first Paralympics, I competed in singles, making it to the finals before losing. I was happy just to be competing, and I think my strong performance surprised everyone, including me.

I also compete against people without disabilities. In fact, most of my play as a junior was in tournaments for "stand-up players." I was ranked among the top 10 juniors in the country.

From a competitive standpoint, I want to beat the guy on the other side of table whether he's sitting down, standing up or standing on his head. The only thing that matters is hitting the ball if it lands on my side of the table. If anything, the competition can be more challenging for the able-bodied player, especially if he is playing me for the first time. Sometimes a stand-up player will assume that my disability makes me easier to beat. That notion is quickly dispelled!

From athletics to business

In the early 1980s, Rainer Kuschall, a friend of mine from Switzerland who was also involved in wheelchair sports, began designing and producing wheelchairs for both sports-

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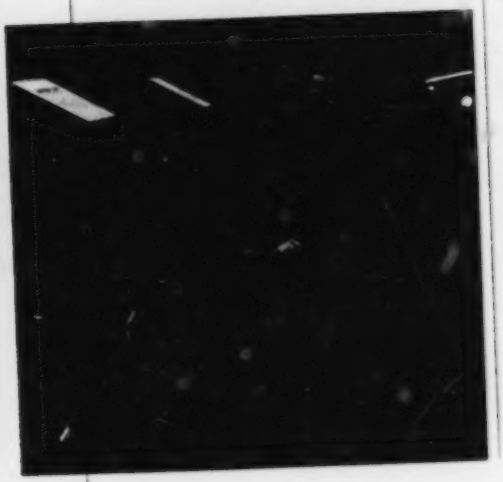
related activities and everyday use. In 1985, another friend, Rod Williams, and I started a company we called Kuschall of America, to import and sell Kuschall's products in the United States.

This particular business was a natural one for me because of my long involvement in wheelchair sports. The beginning of my sports career coincided with the beginning of a period of rapid change and improvement in wheelchair technology. This revolution in chair design was motivated in large part by wheelchair athletes who were demanding equipment that could do better and better competitively. The technology that evolved was soon transferred from sports chairs to everyday chairs.

My position at Kuschall also gives me opportunities for community service. For example, Kuschall has sponsored different sporting events around the country. I also get the chance to meet young wheelchair athletes and do a little coaching.



Dempsey has been a life-long animal lover. "Growing up," he says, "our home was always full of animals. One time we got down to only three dogs. I think that was the fewest pets we ever had."

Life lessons

Sports has taught me lessons that have carried over to my everyday life. I have learned that nothing comes easily; if I want something, I have to work for it. I've also learned to look at losses in a constructive way. Sports has taught me that there are always going to be setbacks along with the wins. The goal must be to learn from the setbacks, take time out to enjoy the wins and then to be ready to come back and do it all over again.

This attitude is valuable in any aspect of life, and in any activity. A child may find that his or her talents are in the arts, for example. Parents can support their children by trying to identify things their child does well, and then encouraging those talents as much as possible. I thank my mother for her constant support and for allowing me the opportunity to try. **EP**

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Destination Atlanta

More than 3,500 athletes to compete in Paralympics

On August 15, just after the conclusion of the Summer Olympics, some 3,500 elite athletes with disabilities will descend on Atlanta for the 1996 Paralympic Games. Everything sports enthusiasts expect of the Olympics will be on display at the Paralympics—nationalism and glory, courage and heartbreak.

At the opening ceremonies, Christopher Reeve, the actor who was paralyzed by a fall from a horse, will be master of ceremonies, and singer Aretha Franklin will entertain. Although the sports events during the 10-day games will take place in 18 different venues, all sites are accessible. The athletes will be competing in such sports as basketball, soccer, track and field, swimming, table tennis, rugby, volleyball, judo, fencing and cycling.

For athletes and spectators alike

The first Paralympics were held in Rome in 1960. Nearly 400 athletes from 23 countries participated. As accessibility and awareness have grown, so, too, have the Paralympics. Atlanta will host 3,500 athletes from 127 nations. The numbers are daunting—550 events in 19 sports, 1,000 coaches and team staff, and 12,000 volunteers. But the Paralympics media spokesperson, Carolyn Koch, says Atlanta is ready.

"Thus far, the response has been wonderful," Ms. Koch says. "Olympic tickets can be tough to get. The Paralympics give everyone a chance to experience the Olympic tradition, to witness the best in the world. Moreover, they're a great opportunity for kids to witness people with disabilities in a positive setting. Hopefully, these athletes can change the lives of those who witness the games."

For the first time ever, the games will be televised in the United States. CBS will broadcast four hours of coverage, an hour a day on August 17, 18, 24 and 25. One hour of highlights from the daily competition will be broadcast every evening on the SportSouth cable channel and on Kaleidoscope, a cable channel focusing on disability issues.

Extraordinary athleticism

The popularity of the Paralympics reflects the world's seemingly endless fascination with athletes. The better the competition, the greater the fascination.

The best in the world are serious, indeed. Consider Canadian Arnie Boldt, a single-leg amputee who has high-jumped 6 feet, 8.5 inches. Kim Brownfield, a paraplegic, bench-presses 602 pounds; the world record is 675. In the men's 800-meter wheelchair race, Scot Hollonbeck's time of 1:40.63 is more than a second better than the world record held by runner Sebastian Coe.

American Tony Volpentest took two

Ticket and travel tips

For general information about the games, contact Atlanta Paralympic Games, 1201 W. Peachtree St., Ste. 2500, Atlanta, GA 30309-3448; (404) 588-1996 (voice); (404) 724-2888 (TTY); (404) 724-2820 (fax). This office can also provide information about volunteering. Tickets to the opening and closing ceremonies and the sports events are available through Ticketmaster at (404) 249-6400.

The Atlanta Convention and Visitors Bureau publishes *Atlanta Now* magazine, a free publication highlighting places to go and things to do in the area. The magazine also includes detailed maps. Call (404) 521-6600.

It's always a good idea to call ahead. Needs vary, and so do obstacles and solutions.

438

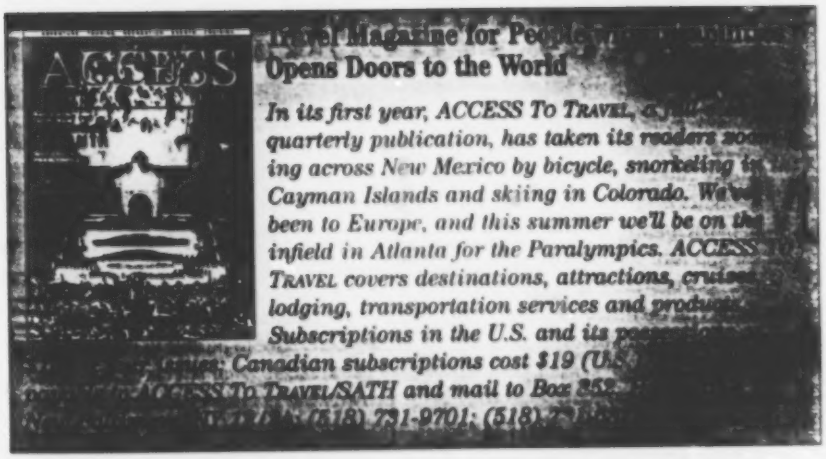
golds at the 1992 games in Barcelona with times of 11.63 for the 100-meter dash and 23.07 for the 200-meter. Born without hands or feet, Tony is the athlete's athlete. He is a college student with a 3.86 grade point average who uses two paint cans topped with padding to prop up his arms while he is in the starting blocks. "I've never asked for special privileges," he says. "I've never felt sorry for myself."

Sydney to host games in 2000

International athletes routinely praise America for the accessibility it provides for people with disabilities. Atlanta wants to take it a step further. "Our plan is to leave a legacy of access in Atlanta," says Ms. Koch.

At the closing ceremonies on August 25, members of the Paralympic Committee of Sydney, Australia, site of the 2000 games, will accept the Olympic flag from Atlanta, just as Atlanta accepted it from the 1992 host, Barcelona. The legacy, now in its fourth decade, has acquired that intangible sought by all athletes: momentum. **EP**

This article was excerpted from "Destination Atlanta" by Bill Fallon, the cover story in the current ACCESS To TRAVEL magazine.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RECREATION

Sports Wheelchairs

by Kristen E. Holmstrand

Racing wheelchairs are just one of many sports wheelchair options for children with disabilities. Photo by Andrew Semel, courtesy of Quickie Designs.

Many children who use wheelchairs lead very active lives, participating in sports for exercise and fun. With the specially-designed sports wheelchairs available today, kids can be faster and more agile athletes than ever before.

Tennis to rugby

Wheelchair manufacturers offer chairs for many different sports—racing, biking, tennis, off-roading, basketball, snow and water skiing, and even for high-contact sports such as hockey and rugby. Designed for speed and maneuverability, sports wheelchairs provide an opportunity for kids in wheelchairs to participate in recreational activities with other children. They can join high school and community track and field and swim teams—competing in separate events, but playing on the same teams as non-wheelchair users.

Who can use a sports chair?

To use a sports wheelchair, children must have at least some use of their hands or arms. For example, bicycle wheelchairs have hand pedals. For racing wheelchairs, children must be able to lift and push with their arms. However, they don't have to be able to grip because racers wear special gloves that provide the necessary friction when in contact with the wheels. If your child is interested in a sports wheelchair, arrange an evaluation with your clinical team and a medical equipment dealer.

Cost considerations

Sports wheelchairs may cost from $1,500 to $2,500; extra or replacement parts add additional expense. The fit of the chair is very important—especially for performance—and because children grow so quickly, you may need to purchase a new chair as your child outgrows an old one. Some companies, however, offer sports chairs with adjustable seats to "grow" with the child.

Meeting the cost

Health insurance policies do not cover sports wheelchairs, so the responsibility for paying for the chair falls on the family. Many families try to get sponsorship or funding from local service clubs and organizations. **EP**

Thanks to Jim Martinson, Shadow marketing manager, Seattle, Washington; Kathryn McDougal, product manager, Quickie Designs, Fresno, California; and Theresa Rapozo, senior marketing coordinator, Quickie Designs, Fresno, California, for their assistance with this article.

Kristen E. Holmstrand is an EXCEPTIONAL PARENT *editorial assistant.*

Superabled and Superspeedy

Amberly, 15, trains with her father, John (right), four times a week. John admits, "I've developed a definite appreciation for the strength it takes to race. It's hard!" Photo by Denis Law.

I have spina bifida. I don't know a whole lot about it, but I do know my legs don't work like other kids' legs. That's okay because I belong to Team Shadow, a team of other disabled—I mean superabled—kids who swim, race wheelchairs, water ski and snow ski.

I got interested in racing at the age of nine, when my parents took me to the University of Washington to learn about adaptive equipment. There we met Jim Martinson, a wheelchair racer who developed the Shadow line of sports equipment for people with disabilities. Jim had these real neat three-wheeled racing chairs. As soon as I tried one, I knew I wanted to race, too. With one of those chairs, I would finally be able to ride on my own instead of in a cart behind my dad's bike.

Since then, I've been to four Junior National Wheelchair Championships and done lots of 5K and 10K road races in the Seattle area. Right now, I'm training to do a 10K road race in Vancouver, Canada. I love this particular race course because both the start and finish are downhill. I'm also training for this year's Junior Nationals which will be held June 22 through 30 in Birmingham, Alabama.

I train with my dad four days a week. On Sundays, Team Shadow practices—first on the track and then in the pool. Rob Cinqmars is our track coach and Jo Ann Brislin, the University of Washington women's swim team coach, and Kiko are our swim coaches. They take a lot of their time to help us.

One of my best memories is when Rob, my coach, couldn't make it to a training session so he told my dad to use his racing chair and go along with me to help me with my pushing stroke. That was fun because I beat my dad and, boy, was he surprised! It made him realize just how hard racing can be. Now he has a lot of respect for wheelchair athletes.

Amberly Austin
Renton, Washington

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Circle #100

Twins

READERS TALK ABOUT: Twins

A Matter of Perspective

Seventeen weeks into my pregnancy, an ultrasound revealed that our first "child" would be *twins!* Our excitement and anticipation were short-lived, however. Eric and Aaron were born at 26 weeks gestation—three and a half months too soon.

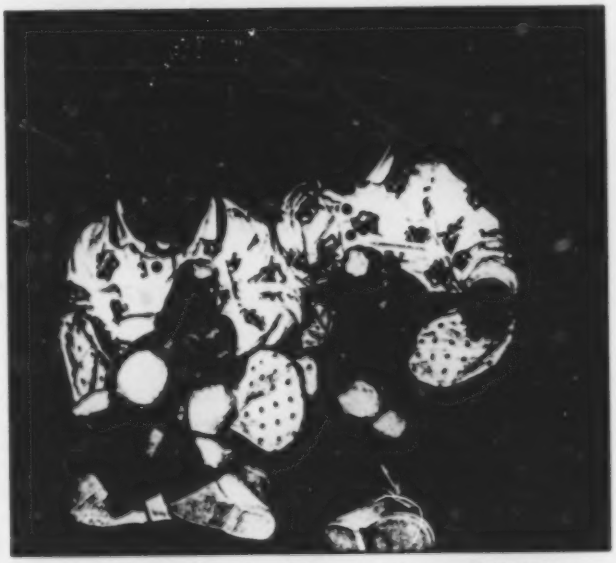
Our lives as parents certainly got off to a rough start, as did the lives of our boys, who were immediately whisked off to the neonatal intensive care unit (NICU). When we finally got to visit, it was difficult to see our babies among all the tubes and wires. They looked like little albino monkeys, covered with fine blond hair.

The boys spent the next three months in the NICU, a stressful roller coaster ride that can be truly understood only by other parents of "preemies." Both boys had many of the problems common to prematurity, including hypotension (abnormally low blood pressure), respiratory distress syndrome, intracranial hemorrhages (bleeding in or around the brain), retinopathy of prematurity (an eye disorder), patent ductus arteriosus (a condition in which oxygenated blood flows back into the lungs rather than circulating to the rest of the body), hyperbilirubinemia (jaundice) and anemia.

Eric's most serious problem was bilateral periventricular leukomalasia (PVL), a condition in which tissue around the brain's ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen. Aaron needed a tracheostomy because of acquired subglottic stenosis (a narrowing of the area beneath the vocal cords and the opening between them), an unfortunate result of his earlier need for a breathing tube. Because of damage to his lungs and airways, he also had bronchopulmonary dysplasia, a chronic condition that would always affect his breathing.

The twins' first year was pretty much a blur. Aaron, who was oxygen-dependent, needed 24-hour-a-day nursing care; Eric was a colicky, fussy baby who rarely slept. We knew Eric had PVL and would probably have a disability but had no idea how mild or severe it might be. Not knowing was the hardest thing to deal with; once he was actually diagnosed with spastic quadriplegia cerebral palsy, we could finally begin to cope.

Although Aaron's problems are more acute now, his long-term prognosis is good; Aaron's problems can be "fixed." We no longer notice his tracheostomy; even to Aaron, it's just a part of who he is—eyes, ears, nose, bellybutton, trach. At the same time, Aaron's more average motor skills are a constant reminder of what Eric might have been. They would be so cute running around the house together.



Aaron and Eric Bissell are identical twins whose very different disabilities stem from medical complications associated with their premature birth. Aaron (left) has bronchopulmonary dysplasia and a tracheostomy; he is now oxygen-dependent only while sleeping. Eric (right) has spastic quadriplegia cerebral palsy.

Despite their differences, the boys share a close bond. It is common for twins to develop their own private "language," but because of Aaron's tracheostomy and Eric's severe speech delays, our twins communicate through an unusual "quacking" noise. Sometimes it sounds like we have ducks in the living room.

In many ways, Eric and Aaron are typical toddlers—each wants what the other possesses. Unfortunately, Aaron has an unfair advantage. As for Eric, I often joke that he never does anything wrong because of my *excellent* parenting skills, but I wish he *could* get into trouble sometimes. I don't see myself as a strict disciplinarian, but I have no doubt that I am more lenient than I would have been if the boys had no problems. A friend watches nervously as Aaron stands on a dining room chair and asks, "Why do you let him do that?"

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT. When readers will be talking about:

- **Positive health care stories:** Tell us about the health care professionals who have made a *positive* difference for your child and family. (August issue; deadline June 1)
- **Talking with your child about sex** (September issue; deadline July 1)
- **Family holidays:** How do you survive large family get-togethers when your family includes a child with a disability? What do you and/or members of your extended family do to help your family and child feel included? (October issue; deadline September 1)
- **When your child grows up:** Where will he or she live, and with whom? Share your dreams, plans and concerns. (December issue; deadline October 1)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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Glancing at Eric lying on the floor like a turtle on its back, I answer, "Because he can."

Richard and I are often asked how we manage. Well, "problems" are all a matter of perspective. I discovered this back in the NICU when we were told that Eric had PVL and Aaron would need a tracheostomy. I was paralyzed with worry and fear but gained some insight on my own situation by observing two other mothers. One woman was upset because one of her twins was temporarily under an oxygen hood; the other was despondent because one of *her* twins had died. All three of us were grieving from different perspectives. I realized that although things could be better, they could also be much worse.

—Cynthia Bissell
Grafton, Massachusetts

Who Needs Me More?

Just two weeks before our third baby was due, Duane and I learned we were expecting two! While my husband frantically located a second bassinet, car seat and swing, I rested and read books on raising twins.

Emily and Elizabeth arrived just 10 days later. Beth, the smaller twin, seemed a little floppy and didn't nurse well initially, but everything improved within a few days and we all went home together. Her older brother and sister immediately gave her the nickname "Kitten," because her cry resembled that of a sad baby cat. We settled in, and I convinced myself all was well.

Still, on the advice of our family doctor, we visited a developmental pediatrician when the girls were a month old. I wasn't worried until he called in a geneticist, who measured Beth's head circumference and the distance between her eyes and then looked at the palms of her hands. The doctors told us they believed she had a chromosomal disorder known as "cri du chat," French for "cry of the cat." They described the syndrome's main characteristics—a cat-like cry, widely-spaced eyes, low-set ears, microcephaly and mental retardation—and ordered a blood test to confirm their tentative diagnosis. But in my heart, I already knew it was true.

My dreams were suddenly shattered—no little girls dressed alike for the holidays or heading off for their first day of school together. I struggled with conflicting emotions. On the one hand, I had the beautiful, bouncing baby girl I had dreamed of, a child who smiled at me and loved to cuddle. On the other hand, I had a tiny baby who cried most of the time, squirmed so much she was hard to hold and never made eye contact. I felt more drawn to hold and play with Emily, but when I did, I felt guilty about leaving Beth out.

I began to obsess about treating the girls equally, no matter what. Whenever I played with Emily, I turned to play with Elizabeth. If I gave Beth a kiss, I immediately kissed Emily as well. I felt particularly self-conscious at family gatherings. I couldn't let anyone believe I was playing favorites with my children, but inside, I was terrified that I really did love one baby more than the other. Emily was any mother's dream, but my heart nearly burst with pride and love as I watched Beth struggle to master the skills her sister learned without effort. I constantly asked myself, Who needs me more? Beth's needs were so much more complex, but Emily's simpler needs were important, too.

"All mothers of twins need to learn to accept their children as individuals," writes Laura Bruns. "This was easy for me; my girls have always been so different." Two-year-old Elizabeth (left, wearing an eyepatch to correct her weak left eye) has cri du chat syndrome, a chromosomal disorder; her twin, Emily (right), does not have a disability.

As the girls grew older, however, I found it easier to relax and enjoy each child for her own unique talents and gifts. All mothers of twins need to learn to accept their children as individuals. This was easy for me; my girls have always been so different. But as I watch Emily help Beth try to stand or get up on her rocking horse, I believe she recognizes the special bond they share.

While shopping with a friend recently, I saw a mother with twin daughters about the same age as mine. Briefly, I flashed back to my original vision of the life I would have with my girls, and tears came to my eyes. But when I arrived home that evening, Emily and Beth greeted me with smiles and hugs, and I said a prayer of thanks for the unique blessing that is my twins.

—Laura Bruns
Coldwater, Ohio

more READERS TALK on page 48

Identical and Different

At a support group meeting, we began discussing dreams in which we envisioned our children with disabilities as completely "normal." Each parent shared a story; then it was my turn. I said, "I don't have to dream; I just look at his identical twin brother."

My husband, David, and I had mixed emotions about my twin pregnancy—we were excited about the novelty and adventure of having twins, but since our daughter, Chelsea, was just two years old, we feared the overwhelming responsibility of caring for three very young children. And it really *was* overwhelming; if it weren't for photos and videos, my pregnancy and the twins' first year of life would be no more than a huge, confusing blur.

Just 20 weeks into my pregnancy, I went into preterm labor and was flown by helicopter to a regional medical center, where doctors diagnosed twin-to-twin transfusion syndrome, a condition in which blood passes disproportionately between one baby and the other through connecting blood vessels in a shared placenta. Doctors told us the twins might not survive, but we refused to give up hope. After a week, I was sent home to total bedrest. Three months later, at 33 weeks gestation, my identical twin boys were delivered via Cesarean section. After six weeks in the NICU battling many of the typical "preemie" complications, it appeared Cameron and Matthew had beaten the odds. They were sent home with a clean bill of health.

Once home, David and I noticed pronounced differences in the boys' development. Although I knew even identical twins could have different dispositions and developmental rates, I began to feel something was seriously wrong. Soon my suspicions were confirmed; at five months of age, Cameron was diagnosed with spastic quadriplegia cerebral palsy and a cortical visual impairment. Our hopes and dreams shattered around us.

But now, two years later, our situation is not as bleak as it once seemed. Although Cameron has global developmental delays, his endless crying has turned to perpetual smiles and giggles. He is a very determined little guy who gives kisses that melt my heart. Like his brother, Cameron charms and delights everyone who makes his acquaintance. Although his tremendous needs continuously challenge our energy, emotions and finances, Cameron is an integral member of the family.

As identical twins Cameron and Matthew Cox grow older, writes their mother, Dana, "their differences become increasingly apparent. People always used to ask if they were twins; now they sometimes ask, 'How far apart in age are they?'" Cameron (left) has spastic quadriplegia cerebral palsy, global developmental delays and a cortical visual impairment.

I must confess that encounters with "typically-developing" identical twin boys have a way of instantly rekindling my grief about Cameron's disabilities. And as our boys get older, their differences become increasingly apparent. People always used to ask if they were twins; now they sometimes ask, "How far apart in age are they?" I worry that they are losing the uniqueness identical twins possess. But late at night, when I watch them sleeping, I can see their alikeness so clearly.

The experience of parenting children with special needs is often described as an emotional roller coaster ride. One thing that has helped us is the ability to network with other families who are dealing with similar situations. About a year ago, I placed a *Search* letter in EXCEPTIONAL PARENT ("Identical Twins Who Are Different," October 1994) and a pen-pal request in *Twins* magazine. I was overwhelmed with wonderful

continued on page 51

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Mostly For Kids

Books and Videos About Living With Seizures

Lee the Rabbit with Epilepsy

By Deborah M. Moss
Woodbine House, Inc. 1989

Read your child this delightful story about the young rabbit with epilepsy.

This brightly illustrated picture book follows the adventures of a small rabbit who has seizures. It tells how Lee and her family cope with the challenges of epilepsy, beginning with Lee's first seizure and initial visit to the doctor, through her diagnosis and treatment. Use it to explain epilepsy to your child with epilepsy, as well as brothers, sisters, and friends. Ages 3-6

Catalog # 133LRB **$12.95**
23-Page Hardcover Book

Mom, I Have a Staring Problem

A true story of petit mal seizures and the hidden problem it can cause: Learning Disability
By Marian Carla Buckel and Tiffany Buckel 1994

Tiffany, a seven year old, describes her experience with petit mal seizures: her feelings, wishes and fears. Written to help adults recognize a hidden problem that could be occurring with a child who has learning problems.

Catalog # 220MSP **$3.95**
24-Page Softcover Book

Julia, Mungo, and the Earthquake

A Story for Young People About Epilepsy

By Saxby Pridmore, MD and Mary McGrath
Imagination Press, 1991

Children who have epilepsy are frequently teased and rejected by other children. This book tells the story of a young girl with epilepsy who becomes the school heroine. It addresses barriers that children with epilepsy confront and can help improve the self esteem of the child with epilepsy. Ages 6-12.

Catalog # 209QKE **$7.95**
47-Page Softcover Book

Dotty the Dalmatian has Epilepsy

From the Dr. Wellbook Collection
Tim Peters & Company, 1993

A delightful illustrated story for young children. This is the story of Dotty the Dalmatian who discovers she has epilepsy. At first Dotty feels embarrassed and afraid, but once she learns to accept and control the seizures she happily goes back to her important job helping the fire fighters save lives. Ages 2-6.

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Introduce your child to other children with epilepsy. "I Have Epilepsy Too" interviews nine children with epilepsy who discuss their experiences with seizures and coping with the physical and emotional aspects of epilepsy. The primary message is that epilepsy is only one part of their lives. A useful video to improve understanding among brothers and sisters. A Family Video Library presentation. (1990)

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"Brothers and Sisters" is divided into two sections. The first half is written specifically for siblings to read with separate sections based on age. The second half of the guide is written for parents and other adult family members (aunts, uncles, and grandparents) to help them understand and handle sibling concerns. (1992)

Catalog # 172BSF **$9.86 EFA Member**
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Epilepsy in the Teen Years

How do teenagers with epilepsy cope with their disorders? "Epilepsy in the Teen Years" explores the lives of four teenagers with epilepsy. They discuss issues of special importance to them including school, sports, friends and driving. A Family Video Library presentation. (1990)

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Circle #283

continued from page 48

responses. I have also become "addicted" to the support and resources available through my computer and modem. I have an account with America Online, a commercial online service, where an active group of parents communicates through the "twins folder" in the Cerebral Palsy Message Area. The knowledge and support we receive from other parents and professionals empower my husband and me to help both boys reach their fullest potential. We are sure that Cameron and Matthew will continue to make us very proud.

—Dana M. Cox
Santa Cruz, California

I Desperately Needed a Break

Doctors told us we were expecting twins when I was in my fourth month of pregnancy. Our son, Oliver, was 10 months old. While the prospect of twins was very exciting, I wondered how we would manage with three babies. Just two months later, at 30 weeks gestation, our identical twin girls were born. After three months in intensive care, Alba and Anastasia were deemed "healthy" and ready to come home. Two months later, they were diagnosed with cerebral palsy.

The next two years were a nightmare. Our family had no medical insurance. The children wouldn't be eligible for Medicaid until all our money ran out—and that didn't take long. The twins were in and out of the hospital with respiratory problems, and because my husband was working two jobs, I ended up caring for three babies alone. My friends, not knowing what to say, kept their distance. I was sleep-deprived, lonely and emotionally drained.

The twins needed round-the-clock care. They rarely slept and were difficult to feed. A feeding session could last for more than two hours, only to have the food come right back up.

But the worst part was the incessant crying. Alba and Anastasia didn't cry like "normal" infants; instead, they let out shrill, piercing screams—screams that never seemed to stop. For the first time in my life, I understood how child abuse could occur. I had to train myself to walk out of the room, leaving the twins screaming at the top of their lungs, and calm myself down before I could return to try to comfort them. I desperately needed a break but could not afford to pay anyone to care for my children, not even for a couple of hours.

Respite care

When my daughters were nine years old, I was invited to become a parent advisor to my state's early intervention advisory council. Even though my schedule with the children was still quite grueling, I was anxious to help other families and accepted the governor's appointment.

At the first council meeting I attended, I pointed out that our state's proposed early intervention legislation, then one month away from a vote, made no reference to respite care services. Despite national surveys showing that parents considered respite services of primary importance, our state's early intervention advisory council had never even discussed the issue. I shared my own experiences with the group. For the cost of one hour of physical therapy—a service early intervention was willing to fund—I could have paid for ten hours of respite care services. Respite care, I explained, might keep marriages together; prevent parents from neglecting, abusing or institutionalizing their children; allow them to spend time with their other children and with each other; and give them a chance to attend to some of their own needs. Three weeks later, the New York State Legislature passed early intervention legislation—and respite care services were included.

Mary Somoza describes her first two years as the parent of identical twins Alba (left) and Anastasia Somoza, now 12, as "a nightmare." But she adds these words of encouragement for other families: "Hang in there and 'tough out' the early years. Things really do get easier..." (Photo: Gerardo Somoza).

It gets easier!

Alba and Anastasia are now 12 years old and will enter junior high in September. They are totally integrated in school and in the community. While caring for their many needs is still a full-time job, both girls lead a full and active life. I am extremely proud of the twins, their older brother, Oliver, 13, and their younger sister, Gabriella, 8.

I have a loving, supportive husband and a close, happy family. It wasn't easy getting to this point, but I would advise other families to hang in there and "tough out" the early years. Things really do get easier as we become more experienced in caring for our very special children.

—Mary Somoza
New York, New York

more READERS TALK on page 52

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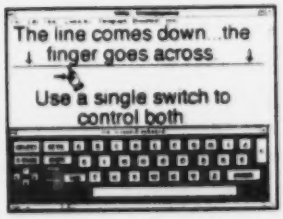

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Circle #93

"Yes, We Have Twins, But..."

When people ask how many children we have, I reply by saying, "We have two five-year-old boys, and a three-year-old girl."

Then comes the usual response: "Oh, you have twins?"

How to explain? "Yes, we have twins," I say, "but they are not really like twins..." In truth, almost the only thing that makes Carter and Daniel twin-like is the fact that they share a birthday.

We were a little scared when we heard we were expecting twins, but friends, relatives, even casual acquaintances treated us like royalty. After the boys were born, we received even more attention. We, too, were very happy, but between coping with the demands of two tiny boys, born four weeks early, and functioning on two to four hours of sleep a night, it took a few months for the reality of it all to sink in.

The reality was that Carter was not developing like his brother. Almost from the start, I had asked our pediatrician questions—"Why doesn't Carter squint at bright sunlight; why doesn't he blink at a camera's flash?" But none of us worried too much until Carter failed to meet several important developmental milestones. After a trail of visits to ophthalmologists, neurologists, geneticists and neurosurgeons, three-and-a-half-month-old Carter was diagnosed with Dandy-Walker syndrome, a condition resulting in several severe disabilities: cerebral palsy, cortical visual impairment, a seizure disorder and hydrocephalus.

Twins Carter (left) and Daniel, 3, and dad Rob Putt admire the scenery at Black Falls, in Canaan Valley, West Virginia. The twins are now five years old.

Sometimes, when I watch Daniel and Carter playing together on the floor, I get a reminiscent flash of the lives we'd expected to have with our twins. It no longer seems sad; it's just not what we had planned.

Each of our three children brings us special gifts, gifts that we might not truly appreciate without the unique perspective Carter provides. He teaches us patience and encouragement when he learns a skill we thought he would never master. He teaches us appreciation for life's small wonders as he delights in the simplest of pleasures—the sound of a drawer being opened and closed repeatedly, the crisp crackling of a plastic bag. And, indirectly, he also gave us Hannah, his little sister. We'd thought our family was complete after the birth of our boys but reconsidered, feeling that Daniel might benefit from another sibling. And Hannah was the result!

"Oh, you have twins?"

How to explain? "Yes, we have twins... but we have so much more than that!"

—Sarah Pavlik
Germantown, Maryland

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Twins

Katherine and **Alexandra Knight,** 2, live in Palm Beach Gardens, Florida, where it doesn't get cold very often. But when it does, these girls are ready! The twins, who live with their parents, Edward Knight and Kristen Kenney-Knight, have spastic quadriplegia cerebral palsy.

"Having two children with disabilities meant I needed help all the time," writes Kristen. "I found it almost impossible to accomplish doctors visits, grocery shopping and other daily chores by myself. And because the twins lacked motor skills, they could not play independently or entertain themselves at all—not even for five minutes. They cried a lot, and so did we."

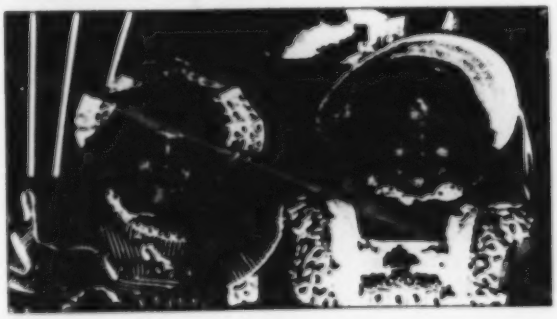
But Kristen says that now, two years later, things are better. The girls have made a lot of progress since their enrollment in the Easter Seals early intervention program last year. They are verbalizing more and using gestures to communicate, and they now have enough muscle control to sit with some support, so independent play has become more possible. And best of all, Kristen declares, for the past few months, the whole family has been sleeping through the night!

"We will always feel pain and sorrow for what might have been," writes Kristen, "but there is also great joy in what we have."

Six-year-old (from left) **Julia** and **Amanda Harr** of LaVernia, Texas compete in a 1993 Easter dress contest wearing outfits lovingly created by their grandmother, Imajean Williams. The twins, now 8, were full-term infants born with no medical complications. But at 10 days of age, Julia suffered an intracranial hemorrhage (brain bleed) resulting in hydrocephalus, cerebral palsy, a visual impairment, a seizure disorder and mental retardation.

Julia and Amanda live with their mom, Barbara, an occupational therapy student at the University of Texas, and their dad, Doc, a retired machinist. Julia and Amanda are second-graders at LaVernia Elementary School, where Julia is included in a regular class and Amanda participates in the gifted and talented program.

"As a first-time parent," writes Barbara, "it was helpful for me to see Amanda's 'normal' development—not to compare the girls' abilities, but to help me set goals for Julia and know what milestones to expect next. For example, through Amanda, I knew when a child could handle baby food, so I introduced Julia to baby food at the same time. When Amanda went into a regular bed, so did Julia. I probably would not have done these things as early with Julia if Amanda's development had not provided some guidance."



Allison and **Brian Totey,** 5, start to get into the holiday spirit when it's time to bake Christmas cookies. Allison and Brian, now almost 10, live in Renton, Washington, with their parents, Janice and Cliff.

The twins, who were born at 28 weeks gestation, had many of the serious medical problems common to premature infants. Shortly after her first birthday, Allison was diagnosed with cerebral palsy.

"It's difficult having one child in a wheelchair and one walking," writes Janice. "Allison constantly asks me why she can't walk like Brian. After all, she says, they *are* twins. It's a very difficult question, but the fact that they are not identical makes it easier to answer. I tell Allison that each of us has different talents, skills and disabilities.

"I've always considered my twins to be fighters, and I know this attribute will help them succeed in life. I love to see their eagerness to try something new, their determination to succeed, and the pride and confidence they gain from every new accomplishment."

Allison and Brian attend regular fourth-grade classes at their neighborhood school. Both show an interest in music; they also love being the center of attention. "I wouldn't be surprised if they become popular entertainers someday," says Janice.

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Four-year-old (from left) **Sheri** and **Jill DeGeorge** live in North Huntington, Pennsylvania, with their parents, Pam and Vince. The day after the girls' birth, the hospital pediatrician expressed concern about Sheri's heart murmur and the fact that both girls were "floppy." The following day, the doctor ordered blood tests for Down syndrome.

"Over the next 48 hours, our families shed many tears and said many prayers," writes Pam. "I remember hoping only one twin would have Down syndrome. But in the end, the tests confirmed the doctor's suspicion—that the twins were identical and that they both had Down syndrome.

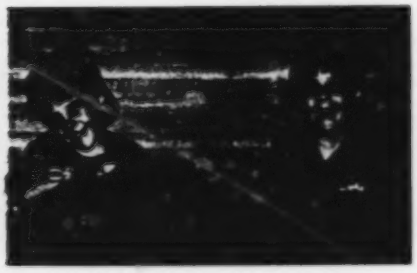
"As I think back to those first few days in the hospital, when we thought we would never experience happiness again, I wish I could have known all the joy and laughter our daughters would bring us. I'm also glad my first wish—that only one of them would have Down syndrome—did not come true. When they look at each other, jabber some words I don't understand, and then start to giggle, my heart just melts inside. I'm so glad they have each other."

Duane and **Debbie Brooks** of Carmel, Indiana show off armfuls of toddlers on Easter Sunday 1993. The Brooks quadruplets (from left) **Lauren, Nick, Tyler** and **Kate** were born, 10 weeks prematurely, after their parents had undergone five years of infertility treatment. As newborns, all four had serious medical problems, but only Kate was left with a disability. "She has a seizure disorder, severely limited vision and virtually no physical skills," explains Debbie. "She also has excellent hearing and a smile that could melt even the coldest heart."

The quadruplets are now five years old. "We are learning to balance Kate's needs against the needs of her siblings—quite a juggling act at times," writes Debbie. "It is frustrating for us that Katie is so often left out of childhood fun. However, Kate's dad is wonderful at trying to include her in as many physical activities as possible. This includes pushing her wheelchair around the house at breakneck speed so she can 'chase' her brothers and sister. Her shrieks of delight more than make up for all the deep scratches we now have in all our doorways!"

For **Chris** and **Marcus Schwab,** 5, having an identical twin means having a best friend who never goes home. The twins, who have spinal muscular atrophy, enjoy a variety of shared activities—from digging in the dirt to playing "bumper cars" with their power wheelchairs. The boys live in Prescott, Arizona, with their parents, Mary and Phil.

"We feel fortunate that we are able to maintain a fairly active lifestyle," writes Mary. "The boys swim for their physical therapy, attend their friends' birthday parties and participate in many community activities. And thanks to our converted van, I can take the boys along when I run errands. In many respects, our lives are much like those of any other family."



She adds, "In some ways, I feel the boys are lucky to have the same medical condition. Each of them knows another person in a wheelchair; it just happens to be his best friend and twin brother."

The Caldwell twins, **Christopher** (left front) and **Timothy** (right front), 16 months, practice standing with a little encouragement from big brother **Zac,** 3, (left rear) and Mom **Elizabeth** (right rear). Doctors believe that Chris and Tim, who live in Marion, Ohio, are the only twins ever to be diagnosed with Alagille syndrome, a rare disorder affecting the liver, eyes, spine, kidneys pancreas, heart and pulmonary arteries. Chris and Tim have serious heart and liver problems and face the possibility of multiple organ transplants in the future.

Although they describe themselves as often exhausted from the demands of caring for two children with complicated medical needs, parents Elizabeth and Richard call the twins "a blessing to the family."

"We take one day at a time," writes Elizabeth, "and try to spell each other as much as we can. Someone from our parent support group is always there in an emergency. The congregation at our church has also been wonderful. I encourage everyone parenting medically fragile children to develop an extensive support system. It can be a lifesaver!"

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

FOCUS ON PERINATAL ISSUES: MOTHERS, BABIES AND BIRTH

What Can Fetal Heart Rate Patterns Predict?

by Robert Perelman

When an infant or young child is diagnosed with cerebral palsy, parents and doctors often believe that the cause of the damage to the child's central nervous system occurred shortly before birth, or during labor and delivery. Actually, most cases of cerebral palsy are unrelated to the birthing process; however, medical professionals and families alike are interested in ways to assure that labor progresses normally.

One way of assuring the normal progression of labor is to monitor fetal heart rate, a good indicator of stress on the fetus during labor and delivery. For example, an abnormal heart rate may suggest that the fetus is not extracting enough oxygen from the mother's bloodstream through the placenta and umbilical cord. Historically, doctors have monitored fetal heart rate using a technique known as intermittent auscultation, which involves listening to the fetal heartbeat through a stethoscope-like apparatus. But electronic fetal monitoring (EFM), first introduced in the late 1960s, has increasingly become the technique of choice and is now used during three out of four deliveries in the United States.

EFM usually involves attaching an electrode (or monitor probe) to the fetus following rupture of the fetal membranes and resultant loss of amniotic fluid (commonly referred to as the time when a woman's "water breaks"). This electrode transmits the fetal heart rate to an outside monitor screen.

EFM was intended to help doctors more accurately identify the occurrence of fetal heart rate patterns during labor that may indicate intrauterine hypoxia, a potentially dangerous reduction in the supply of oxygen to the fetus. The early detection of such problems would give doctors an opportunity to intervene—usually with an emergency Cesarean section—before the occurrence of fetal death or irreversible brain injury leading to cerebral palsy and mental retardation.

It all seemed so logical that EFM quickly became commonplace delivery room technology, without any research that conclusively proved that this new technique was indeed more beneficial than intermittent auscultation. Most studies of EFM involved too few infants or failed to follow the infants long enough after birth to confirm that certain heart rate patterns detected through EFM were actually associated with relatively uncommon outcomes such as cerebral palsy.

Recently, however, a group of medical scientists reported the results of an EFM study involving 156,000 full-term infants who lived for at least three years. The study, published in the *New England Journal of Medicine* on March 7, 1996, looked at the association between certain abnormal fetal heart rate patterns, detected through EFM, and a later diagnosis of cerebral palsy. Although two patterns of fetal heart rate were associated with cerebral palsy, the researchers found that doing a C-section in such cases was not preventive; infants with these abnormal heartbeats who were delivered by C-section were just as likely to be diagnosed with cerebral palsy as those delivered vaginally. Furthermore, most of the infants in whom these abnormal heart rates were detected did not develop cerebral palsy. (The study did not consider abnormal outcomes other than cerebral palsy, however.)

Based on their data, the researchers estimated that EFM use leads to approximately 9,300 emergency C-sections in 100,000 full-term deliveries. However, such interventions prevent cerebral palsy in only four of these cases. This means that for every child for whom cerebral palsy is prevented as a result of EFM, 516 unnecessary C-sections may be performed.

Because as many as 12 percent of C-sections lead to medical complications, some serious, for both mother and baby, the researchers conclude that the use of EFM often presents more risks than benefits. "We need to consider how to balance the possibility of helping the small number of babies threatened by death or irreversible brain injury... against the possibility of harm to some of the very large number of mothers and babies who, despite similar heart rate patterns and other clinical findings during delivery, would not benefit from intervention," they write. "What tradeoffs are reasonable?"

Electronic fetal monitoring is often reassuring to clinicians because the technique provides consistent information during the progress of labor. In addition, such monitoring may detect rare and potentially catastrophic complications. Unfortunately, there is little evidence to confirm that EFM is superior to intermittent auscultation or that it truly results in a reduction of birth-related disabilities such as cerebral palsy. This does not mean EFM is not useful and indicated for certain situations, but rather, that clinicians and researchers must rethink the "whys" and "whens" of its appropriate use. **EP**

This is one of a series of articles prepared in collaboration with the National Perinatal Association (NPA, 3500 E. Fletcher Ave., Ste. 209, Tampa, FL 33613-4712; 813/971-1008; 813/971-9306, fax). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time-of-birth) health issues from preconception through infancy. The organization fosters optimal perinatal care by promoting education, supporting research, influencing national priorities and encouraging collaboration among all concerned constituencies, including health care providers and consumers. Robert Perelman, M.D., is the current NPA president and an associate professor of pediatrics at the University of Wisconsin at Madison.

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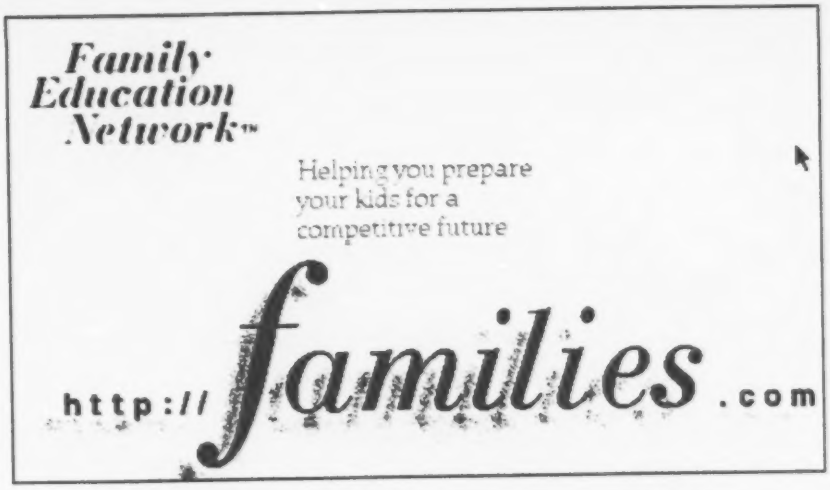

Virtual Community

EXCEPTIONAL PARENT goes on-line with the Family Education Network

by Mike Cisneros

We're looking ahead to an extraordinarily exciting year on the Internet. The U.S. telecommunications industry is undergoing major reorganization, which will result in faster, cheaper, better and wider access to on-line services. In an astoundingly short period of time, the World Wide Web's popularity has soared, and the web itself has evolved into a reliable resource, a brand-new form of entertainment and a virtual community, bringing together people with common interests from all around the globe. As more people connect to the Internet and gain access to electronic mail (e-mail), communication that used to take days now takes minutes.

In our Silver Anniversary year, EXCEPTIONAL PARENT is joining the electronic revolution wholeheartedly. As announced in our April issue, the magazine is working with the Educational Publishing Group to develop the Family Education Network (FEN), a comprehensive new website for parents and families. Although the official launch date isn't until early September, several of the site's areas and features are already on-line (http://families.com). This venture will give EXCEPTIONAL PARENT the opportunity to share more information with more people than is currently possible through the print media. FEN will bring together, under one virtual roof, the kind of information and support that once took months or years to gather.

It's what you want it to be

With a design utilizing the newest and most innovative web technologies, FEN will be a constantly growing resource for information about parenting, education, disabilities, health, careers, finance, politics and other topics. It will provide news of both local and national interest and offer advice on how parents can be more effective advocates for their children.

FEN will be customizable; when you first connect, your personal interests will be noted, and the site's environment will be tailored to those preferences each time you return. If you have a specific interest, FEN will notify you of news on that topic each time you visit. Think of it as the world's largest Sunday paper, with your favorite sections and articles separated out and waiting at the breakfast table.

FEN is organized by "channels," much like a television set. Current channels include parenting, education, money, careers and politics. Within each channel, there are topics of specific interest to the families of children and young adults with disabilities. Here, as within the past quarter-century of the magazine, EXCEPTIONAL PARENT will provide helpful information to parents and professionals. You'll see more *Search* and *Respond* letters (to which you'll be able to reply electronically), reactions to magazine articles and additional information on stories we've been covering. You'll also be able to join electronic conversations with other visitors to FEN. The opportunities are vast, and we intend to take advantage of them.

But FEN will be more than an on-line information service; the area will be a community where parents, professionals and children can connect with each other. This kind of informal networking could be the most exciting element of FEN.

Let the kids have a turn

FEN will also have areas where children can participate in fun activities and enjoy programming intended especially for them. FEN will be the on-line equivalent of a clean, well-lit, accessible playground, where children can spend time with their peers in a safe, fun and enriching environment.

One of the wonderful things about the Internet is that it makes communication much easier for everybody. On the web, everyone is on equal ground, regardless of age or disability. Our hope is that FEN will give kids a supportive virtual community, where they can meet new friends and communicate independently and confidently.

Coming attractions

New features and channels are constantly being added. Eventually, EXCEPTIONAL PARENT plans to host scheduled on-line chats, where experts can interact with chat participants. A newsletter for FEN members and other off-line goodies are also in the works. Be on the lookout, both in the magazine and on FEN, for announcements of new events. And check FEN out at http://families.com, and see what the buzz is all about. **EP**

Mike Cisneros is an EXCEPTIONAL PARENT editorial assistant.

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NIKE Promotes Sports And Fitness for All

P.L.A.Y. program reaches out to all children

America has always been fascinated by sports in general and by athletes in particular. In fact, more and more individuals with disabilities are enjoying athletic activities, both as participants and as spectators. Today we know how sports and physical fitness can contribute toward physical endurance and emotional well-being. In addition, the positive values of sports can help promote a fit and healthy lifestyle for children that will endure into adulthood.

NIKE believes that every child should have the opportunity to enjoy sports and fitness. That's why ***NIKE*** created P.L.A.Y., which stands for Participate in the Lives of America's Youth. This program is designed to promote sports and fitness and to improve playgrounds, clubs and other recreational facilities for children. ***NIKE*** is also involved in the Oregon Special Olympics as one of many facets of the P.L.A.Y. effort.

Over the years, ***NIKE*** has contributed resources to the Boys & Girls Clubs of America. The national office of the Boys & Girls Clubs in Atlanta, Georgia, has long recognized the importance of including children with disabilities in club programs. Local clubs are encouraged to broaden the scope of their programs and forge connections between the clubs and existing organizations for children with disabilities.

Teens themselves have organized activities for children with disabilities through their local Keystone Clubs, the teen leadership program sponsored by the Boys & Girls Clubs. Two such projects, one in Newark, New Jersey, and the other in Royal Oak, Michigan, recently won awards as the best Keystone Club projects.

Newark's Keystone Club, called Spirit Raisers, worked with blind youngsters in Newark to help them prepare for competition in swimming, bicycling, horseshoe throwing, track and goal ball. Subsequently, some of the blind teens joined the club's chorus and drama group and became active participants in club activities. The Keystone Club in Royal Oak won for their Youth Abilities project, a special program for children with disabilities run in collaboration with agencies in South Oakland County. The club organizes an eight-week T-ball program during the summer for children with disabilities. Every child who participates receives a trophy donated by the community.

NIKE is committed to creating equal opportunities for all children so that all can participate. As part of its P.L.A.Y. program, athletes Michael Jordan and Jackie Joyner-Kersee, co-chairs of P.L.A.Y., are appearing in ads entitled "What if there were no sports?" The two athletes have also recorded a message on a toll-free phone number (800/929-PLAY) the public can call to get information on how they can get personally invoived in P.L.A.Y. Callers also receive the phone number of the Boys & Girls Club closest to them and can receive a ***NIKE*** P.L.A.Y. brochure.

NIKE's P.L.A.Y. program has several key elements:

- ***NIKE*** has given the Boys & Girls Clubs of America $1 million over the past three years to develop programs and expand membership.
- ***NIKE*** has mounted a multi-million dollar effort to support children's sports and fitness programs throughout the country, including sponsorship of races, tournaments, clinics, camps and after-school programs.
- ***NIKE*** athletes are giving their time and money to help fund and support children's sports programs around the country.
- ***NIKE*** is encouraging children's activism by establishing a Kids' Advisory Board made up of television stars and five Boys & Girls Club Youth of the Year winners.
- ***NIKE*** uses old recycled ***NIKE*** shoes to resurface playgrounds and courts at various sites around the country.
- ***NIKE*** has hosted five Youth Summits designed to facilitate ways in which children can actively help their communities create and preserve sports and fitness programs.
- ***NIKE*** has mounted a 10-city tour of P.L.A.Y. Days free to the public designed to give kids the opportunity to try new sports. **EP**

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

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CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

Looking For Friends:
Unmet Needs of Children with Disabilities

We start socializing our children early. Swimming classes at the Community Center. Play groups. T-ball, soccer, and hockey start well before a child walks into kindergarten. Recreational and leisure activities are valued as successful teaching tools.

By
Peggy Mann Rinehart

But families who have children with chronic illness or disability find providing their children with opportunities for recreation is on the bottom of their wish list—if it even makes it to their wish list.

Understanding what activities, behaviors, and relationships characterize resilient kids and families is the overall goal of Project Resilience, a longitudinal study of factors predicting competence in children with chronic illness and disability being conducted in the Division of General Pediatrics and Adolescent Health at the University of Minnesota.

Recreation...
Refeshment of strength and spirit after work.

First Things, First

While family-centered care has been the buzz word for children and youth with disabilities for the past decade, little is known about family satisfaction with services. Satisfaction surveys conducted in 1980 (Leyser, 1988; Polifka, 1981) suggest that parents they surveyed were satisfied with special education services even if services were provided in segregated classrooms.

Since then, many families have discovered that normalizing life experiences foster the development of psychological and social competence. Many recognize the need for enhanced recreational experiences, the need to find a place in communities. Nonetheless, when asked, parents think of "services" as they relate to a child's medical, educational, or financial needs.

While parents often express satisfaction with services their children are currently receiving, little has been done to understand how needs are not being met for families. That's why Sarah A.M. Axtell and Associates decided to look at a small portion of the interviews and surveys conducted as part of Project Resilience.

"Not only were we interested in the parents' perceptions of the adequacy of services," Axtell says, "we wanted to understand just what parents perceived were unmet needs for their children."

Satisfaction

Overall, in this study of 187 families with children aged 6 to 24 months when first interviewed, parents were satisfied with services provided. They were asked to rank primary medical care, specialized medical care, physical therapy, occupational therapy, special education/early intervention, nutrition, respiratory therapy, specialized nursing care, case management, speech therapy, home health care, respite care, counseling, and specialized dental care.

On a scale of 1 (not at all adequate) to 5 (extremely adequate), mean ratings ranged from 3.6 to 4.5. Specialized medical care received the highest rating of 4.5 and respite care received the lowest rating of 3.6. However, less than 10 percent families interviewed were receiving any form of respite care.

Typically, when families received a service,

Unmet Needs
Turn to page 64

they reported at least moderate satisfaction with the adequacy of the service.

Unmet Needs

Interviewers asked open-ended questions to get at the unmet needs of families. Interviewers helped families by giving them a "response" card listing possible services. Twenty-eight percent of families interviewed could identify services their children needed but were not receiving. This may seem like a relatively small percentage; however, these are unmet needs of infants and toddlers. Parents may have not yet learned the range of services that are available. For these young parents, it may be tough to ask for a service if you don't know it exists—or could exist.

At this stage of their children's lives, medical needs take up more of the parents' time than the children's social needs. Still, three families expressed a need for play and socialization services—services not listed on the response card. The developmental needs of children with chronic illnesses and disabilities are fundamentally the same as those of all other children. Issues of recreation increase as children approach school age. Over time, parents are likely to become more knowledgeable about service systems and will be more able to identify what their children need.

Even at this early age, parents most frequently reported their child was not receiving necessary occupational therapy (therapy that focuses on fine motor control), physical therapy, speech therapy, respite care/child care, and special education.

Parents Report Reasons for Unmet Needs

Service	*Frequency*
Lack of funding	12
Service unavailable	18
Family choice	7
Service difficult to access	5
Child not eligible for service	4
Provider decision	4
Inadequate service	3
Communication difficulties	3
Lack of information	3
Limited resources	2

When interviewed, parents from 52 families provided these reasons for why their needs were unmet.

Barriers

Money seems to be the greatest barrier to service delivery. Typically, child care is not covered by family insurance policies even when specialized care is needed. Likewise, physical, occupational, and speech therapy are funded through schools rather than medical insurance. Often these children do not receive services until they are enrolled in center-based programs. For 15 percent of the families interviewed, necessary services or personnel were not available.

In addition to the barriers identified by the families in this study, others say that inadequate coordination of services contributes to unmet needs. That begs the question: Who is responsible for seeing that the needs of the child and the family are met? The children involved in this study represent a wide range of physical disabilities, chronic conditions, and illnesses. That's because there is a fundamental belief that, regardless of condition, children with disabilities and their families have many of the same fundamental needs. However, those children with multiple disabilities clearly had more unmet needs. Coordination of services and monitoring of service needs may be particularly important for families of children with multiple impairments.

The material presented here is based on **"Unmet Service Needs of Families of Young Children with Chronic Illnesses and Disabilities,"** co-authored by Sara A.M. Axtell, Ann W. Garwick, Joan M. Patterson, Forrest C. Bennett and Robert Wm. Blum, and published in the *Journal of Family and Economic Issues*, 16(4), Winter, 1995. This represents some early findings of Project Resilience, a longitudinal study of factors predicting competence in children with chronic illness and disability.

The Center for Children with Chronic Illness and Disability is a research and training center dedicated to the study and promotion of the psychological and social well-being of children with chronic conditions and their families.

The mission of NCYD is to improve the health and social functioning of youth with disabilities by technical assistance and consultation, disseminating information, and increasing coordination of services between the health care system and others.

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WHAT'S HAPPENING

Publications

• *Special Children*, a quarterly newsletter, reaches out to parents of multiples (twins, triplets or more) with disabilities. Each issue includes anecdotes, resource lists, stories from readers and quick tips. For a one-year subscription, send $10 to *Special Children*, c/o Sharon Devo, P.O. Box 8193, Bartlett, IL 60103; (708) 213-1630.

• The completely revised sixth edition of the highly acclaimed *A Primer of Brain Tumors* is now available. Twelve chapters, 20 illustrations and an extensive index provide an understandable yet comprehensive overview. Single copies are free. Contact the American Brain Tumor Association, 2720 River Rd., Des Plaines, IL 60018-4110; (800) 886-2282; (847) 827-9910.

• Two free publications from the National Institute on Deafness and Other Communication Disorders provide valuable information about communication. *Organizational Resources for Consumer Information*, a concise resource list, is available for each of the following areas: hearing, balance, smell and taste, voice, speech and language.

The brochure *Facts About Telecommunications Relay Services for Individuals with Communication Impairments* includes a brief description of relay services and how to use them a list of national resource organizations, and toll-free telephone numbers for relay services all over the country. Contact the NIDCD Information Clearinghouse, 1 Communication Ave., Bethesda, MD 20892-3456; (800) 241-1044 (voice); (800) 241-1055 (TTY); (301) 907-8830 (fax).

• *Access for All: A Guide for People with Disabilities to New York City Cultural Institutions* (second edition) provides detailed information on the accessibility of more than 300 NYC cultural institutions including Broadway and off-Broadway theaters, museums, galleries, concert halls, performing arts centers, zoos and gardens, stadiums and arenas, landmarks, libraries and historical sites. The 210-page book catalogs parking, entrances and alternate entrances, availability of auxiliary aids and services, wheelchair locations, rest rooms, telephones and water fountains. The book costs $5 and is available from Hospital Audiences, 220 W. 42nd St., New York, NY 10036; (212) 575-7676 (voice); (212) 575-7673 (TTY).

Networking

• In Touch with Kids (ITWK), a free worldwide program started in 1985 by the National Spinal Cord Injury Association, is a support network for children with spinal cord injury or dysfunction, and their families. ITWK provides an opportunity for sharing ideas, feelings, resources and innovative problem-solving techniques with other families. For more information, contact Lyman Phillips or Joseph Schleifer, ITWK/NSCIA, 545 Concord Ave., Ste. 29, Cambridge, MA 02138; (800) 962-9629.

• A new support network is available for families dealing with Cowden syndrome (multiple hamartroma disease), a rare genetic disorder that causes skin overproduction, resulting in the growth of excess skin inside and outside the body. Contact the Cowden Syndrome Network, c/o Sandra B. Tolman, 26C Kennard Rd., Windham, ME 04062; (207) 892-2369.

• A new support network is available to families dealing with nephrogenic diabetes insipidus (NDI), a rare genetic disorder. NDI causes the kidneys to retain too little water in the body, resulting in severe dehydration. Early symptoms include excessive thirst and frequent urination. For more information on the network, contact Anne-Lynne Keplar Samole, 235 N. Hibiscus Dr., Miami Beach, FL 33139; (305) 532-7399 (voice/fax).

continued on page 66

FUNNY AS A CRUTCH by Frank Bernard, Jr.

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FRANK

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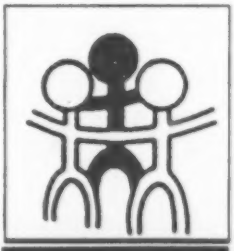
The above was adapted from an ABLEDATA FACT SHEET ON SCOOTERS written by Katherine Belknap, ABLEDATA program specialist. This fact sheet and others are available free from ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY); (301) 587-1967 (fax). The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 22,000 products for persons of all ages who have a cognitive, sensory or physical disability.

continued from page 65

Arthrogryposis Video

The National Arthrogryposis Foundation, Inc. (NAFI) has produced a video entitled *Coping with Arthrogryposis: A Parent's Perspective*, available free of charge to interested individuals. The video touches on emotional and psychological issues as seen through the eyes of parents and gives insight into the coping process. Arthrogryposis is a condition in which an infant is born with multiple joint contractures. Contact NAFI, 3356 S. Cove Trace, Birmingham, AL 35216; (205) 823-0786.



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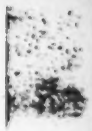

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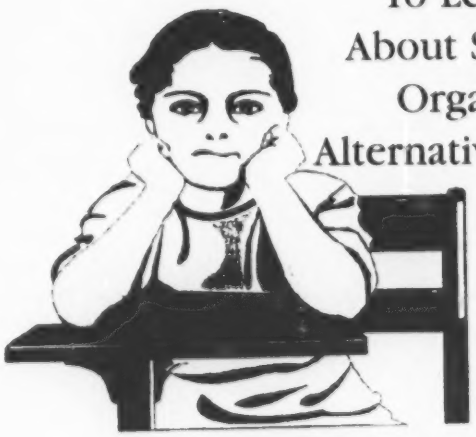

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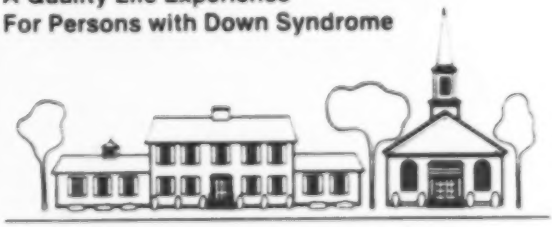

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Circle #291

Down Syndrome and Hip Dislocation

by Richard L. Shindell, M.D.

At the request of ASK THE DOCTOR columnist David Hirsch, Richard L. Shindell, M.D., answers this month's question. Dr. Shindell is a pediatric orthopedic surgeon in Phoenix, Arizona.

Q Our two-year-old daughter has Down syndrome. She started walking at 17 months and, about three months later, began "clicking"—partially dislocating—her hip. She does this at will, usually while at rest, and does not appear to experience any discomfort while doing it.

Our daughter's physical therapist didn't seem concerned, so we didn't think any more about it until her pediatrician referred us to an orthopedist. The orthopedist recommended that our daughter undergo a surgical procedure called a "varus osteotomy with an acetabuloplasty and a capsular reefing." He told us that if we do not correct this dislocation problem, she will soon experience hip pain, may eventually refuse to walk and could end up with a permanent hip deformity.

Our daughter also had open heart surgery at four months of age to correct a ventricular septal defect, a heart defect in which there is an abnormal opening in the wall (septum) separating the heart's right and left ventricles. Because she still has a slight heart murmur due to a cleft in her heart's mitral valve, her cardiologist is concerned that hip surgery could cause an infection in her heart.

Is this type of hip dislocation problem common in children with Down syndrome? What does the recommended surgical procedure entail? How successful is it likely to be?

A Your daughter sounds fairly typical of children with Down syndrome who develop hip dysplasia. Hip problems usually occur between two and four years of age, and, typically, the child will be somewhat late in walking. Hip dislocations, in which the femoral head (ball) comes at least partially out of the acetabulum (hip socket) are not painful initially but later may result in a fixed and painful deformity.

The three procedures mentioned in the letter have the common goal of creating a deeper and tighter socket in which the hip will be more appropriately oriented. Quite often, the hip socket is somewhat deficient and steeply sloped. The procedure known as an acetabuloplasty involves making a bone cut above the socket and trying to reorient the socket downward, which can provide a better support shelf for the femoral head.

The second procedure, the varus osteotomy, involves taking a small wedge out of the top part of the femur (thigh bone) to decrease the angle at which the ball approaches the socket. This, too, allows the hip to be seated more deeply in the socket.

The third procedure, capsular reefing (sometimes called capsulorrhaphy), simply tightens the ligaments that hold the hip in the socket. These ligaments are often quite lax in children with Down syndrome. These three surgical procedures are typically followed by six to eight weeks in a spica case, which immobilizes the joint, and then several months in a brace.

Unfortunately, despite surgery, hip problems sometimes recur. However, this does not mean the surgery is not worthwhile; hip dysplasia is much easier to deal with in its early stages.

The possibility of infection is a valid concern with a child who has heart problems, but infection can usually be easily prevented with the use of antibiotics around the time of surgery. I would suggest that the family mention this concern to the orthopedic surgeon as a reminder. **EP**

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

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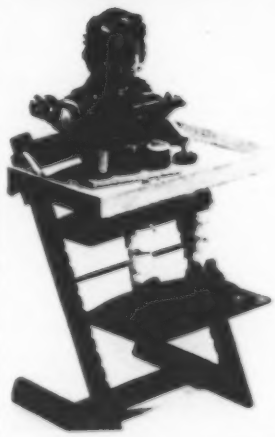

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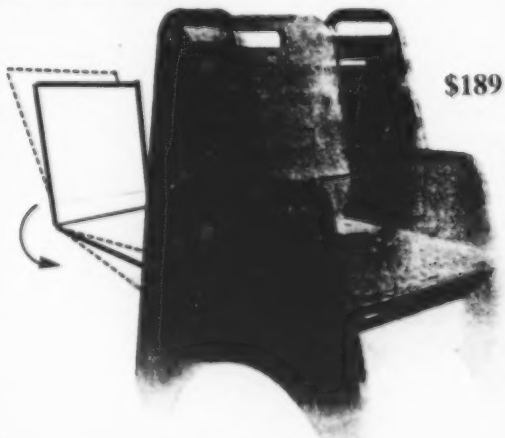

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PART TWO

Guardianships and Other Protective Assignments

by Frank L. Brunetti

Q Our 14-year-old son has moderate to severe mental retardation, but is in relatively good physical health. He attends a special pre-vocational training program in our school district.

When our son is an adult, we believe he will need help managing his everyday life so other people do not take advantage of him. We have prepared a will so that the property and money we have designated for him will go to a special needs trust, leaving him eligible for government support programs.

We have been told we should also appoint a guardian or conservator as soon as possible. But we thought that would take place after our deaths. Do we need to appoint a guardian or conservator while we are still alive? If so, why?

A *In Part One of "Guardianships and Other Protective Assignments" (April 1996), I explained that your will and the special needs trust you have established for your son are not enough to prepare him for your deaths. Appointing a guardian or conservator ensures that someone will look after your son and his affairs, both before and after he is an adult. Last month's column outlined the responsibilities of a guardian. Now I will explain the process of appointing a guardian and the option of choosing a conservator instead of a guardian.*

Guardianship proceedings

As an adult, your son may not be able to act for himself or defend himself against unscrupulous persons. Any contract he signs may be legally enforceable against him. Through a guardianship application, your son could be declared "incompetent" by the court, and, thus, could not be held legally accountable for himself. The appointed guardian would be his legal protector.

A guardian is usually appointed from among close relatives or friends. When no family members or friends are willing to serve, the court selects a guardian.

A guardianship application is a court proceeding. The proposed guardian must:

- have an attorney prepare a legal document indicating that your son is "of unsound mind and unable to manage his affairs" and asking the court to find him incompetent (referred to as "filing a complaint" with the court);
- provide affidavits describing your son's real and personal property; and
- provide affidavits from physicians attesting to your son's mental and physical conditions.

Because of the serious nature of the proceedings, states require proof that the proposed guardian (called the "plaintiff") has notified the "alleged incompetent"—in this case, your son—of the filed complaint. In many states, the court will appoint an attorney to represent the person who has been alleged incompetent. Attorney's fees are paid out of the funds owned by the "alleged incompetent" or, if no such funds exist, by the proposed guardian. The attorney will conduct an independent investigation and report all findings to the court.

Guardianship applications usually involve a non-jury hearing before a judge. The proposed guardian must testify under oath about his or her knowledge of your son and his financial affairs. In other words, the testimony of the proposed guardian must support the claims made in the complaint. After reviewing testimony from the proposed guardian and the affidavits of your son's physicians, the court may conclude that your son is unable to govern himself and manage his affairs. If so, it will enter a judgment of incompetency—declare your son legally "incompetent"—and approve the guardian's appointment.

Before letters of guardianship are issued, the guardian must "post bond." This means the guardian must obtain a surety bond, or insurance policy, to protect your child against any wrongful acts by the guardian, such as embezzlement. The insurance company would cover the cost of any stolen funds and would have the responsibility to pursue the guardian to recover the money.

Once the court has entered a judgment of incompetency, your son would become a ward of the state. This gives the state full authority over his person and property, and greatly affects his legal rights. An "incompetent" cannot vote, cannot enter into contracts and cannot be held liable for criminal acts.

Guardianship proceedings may cost from $2,000 to $3,500. These costs include court costs and compensation for attorneys (one for your son, one for the proposed guardian) and for the physicians who file affidavits. Therefore, if local law allows, you should consider including more than one family member in the application so that your son will have co-guardians. That way, if one guardian dies, the other can continue carrying out guardianship duties without the need to file a new application. Of course,

In this column, attorney Frank L. Brunetti answers questions about any aspect of estate planning involving a child with a disability. Mr. Brunetti, a professor of law and taxation at Fairleigh Dickinson University in Teaneck, New Jersey, has written extensively on the topic of estate planning for families who have children with disabilities.

Send questions to: Estate Planning, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).

multiple guardians must be able to agree on financial and medical decisions.

A guardian's authority ends when the ward dies or if the ward later becomes competent in the eyes of the court (which may happen in some guardianship situations; for example, a situation involving an individual who recovers from a mental illness). A guardian's authority also ends if he or she resigns or is removed by the state. In these latter cases, the co-guardian can take over or, if one was not appointed, the court will choose a new guardian.

Conservatorship

The law in most states allows for the appointment of a conservator, rather than a guardian, in cases where a person would be not be considered legally "incompetent," but, rather, unable to care for his or her property due to "advanced age, mental weakness or physical incapacity." Generally, conservatorships are set up for elderly people who are not incompetent, but who need some assistance conducting their financial affairs because their mental faculties are not as keen as they once were. Though your son is only 14 years old and not able to live on his own, he may have the intellectual ability to manage minor day-to-day affairs. If this is the case, you may want to consider the appointment of a conservator, who can help him manage larger financial concerns.

Since competency is not an issue, a conservator would not have power over your son's person, just over the management of his property. Some states also allow limited conservatorships, in which the conservator's power would depend on your son's particular circumstances. For example, a conservator's power can be limited to managing only certain, specified financial assets. In either case, your son's civil rights would be unaffected—he could still vote and make contracts. Conservatorship may be an especially useful option if your son has no close relatives to manage his property, or if family members are at odds over who should control his assets.

Because the appointment of a conservator also requires a court proceeding, applications can be costly. A more cost-effective alternative might be to have your son sign a durable power of attorney, which gives a specified person the power to manage your son's financial affairs. (This person is referred to as the attorney-in-fact, but does not actually have to be an attorney.) The durable power of attorney would remain in effect even if your son became unable to make sound decisions (for example, if he fell into a coma). You should require the attorney-in-fact to post a surety bond to prevent loss of your son's assets in the event of theft. **EP**

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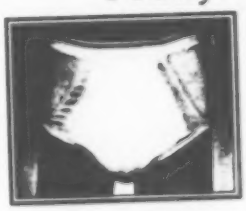

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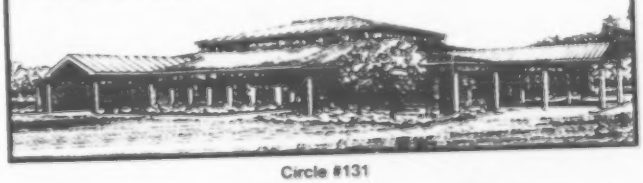

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Equipment Exchange Programs

by Richard Epstein

I've received letters from several readers with self-insured health insurance policies who reported limitations in their insurance coverage for durable medical equipment (equipment intended for long-term use). Although I still cannot suggest a mechanism by which people can persuade health insurance companies to approve the purchase of durable medical equipment that is excluded from the contract, I am happy to report on a new way for parents in many states to locate inexpensive, used durable medical equipment.

In 1988, the federal government passed the Technology-Related Assistance for Individuals With Disabilities Act. That law, generally known as the "Tech Act," provided for the development of state programs to help consumers learn about and access disability-related technology. The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) serves as the technical consultant for Tech Act programs. (See "State Assistive Technology Programs" in EXCEPTIONAL PARENT's 1996 Resource Guide, January, for a state-by-state listing.)

Each state's program is unique; however, most states offer certain basic services, including information and referral, assistance in obtaining funding for technological devices and opportunities for consumers to try out different types of equipment.

Now, according to RESNA, many Tech Act programs are also offering equipment exchange or recycling programs. Exchange programs match people who have agreed to sell or donate specific durable medical equipment with people who need such equipment. Available equipment—which may include wheelchairs, scooters, vans, wheelchair lifts, augmentative communication equipment, specialized computers, hospital beds, prosthetic devices, stair lifts, walkers and crutches—may be listed in a newsletter or on a BBS (a computerized bulletin board system accessible through a computer modem). Or the information may be accessed through a telephone call to the program office. Equipment usually remains in the owner's garage or basement until sold.

Equipment recycling programs operate somewhat differently. In this case, the equipment is usually stored in a central location and may be refurbished before going to a new owner. Both new and used equipment may be available.

In some states, the Tech Act programs operate an exchange or recycling program directly. In other states, programs are operated in cooperation with other organizations. Tech Act programs do not usually charge fees for listing items, although there may be a fee to have a photograph of the item displayed in a catalog of available equipment. Some Tech Act programs have certain restrictions, usually related to safety or liability issues, on equipment that may be listed.

Although most items available through such programs are relatively inexpensive, guarantees or warranties are not usually offered. That may not make much difference with a walker or a manual wheelchair, where you and/or a medical equipment dealer can examine the item thoroughly before purchase. However, the lack of a warranty may be a significant issue with items such as power wheelchairs or lifts, where it may not be possible to thoroughly examine or test the electronics before purchase, and where repairs can be very expensive.

According to RESNA, Tech Act programs in the following states currently operate equipment exchange programs: Alaska, Arkansas, Delaware, Georgia, Illinois, Indiana, Iowa, Kentucky, Minnesota, Mississippi, Montana, Nebraska, Nevada, New Hampshire, New Jersey, New York, North Carolina, Oregon, Pennsylvania, South Carolina, Utah, Vermont, Virginia and West Virginia. Many of the programs are new, however, and may have only limited listings for used equipment at this point.

The following states' Tech Act programs, according to RESNA, currently operate equipment recycling programs: Georgia, Illinois, Kentucky, Mississippi, Nevada, New Hampshire, New York and Oklahoma. Several of these programs focus only on computers and computer-related equipment.

If you have durable medical equipment or computerized equipment to donate or sell, or if your child needs equipment that is not covered by your health insurance policy, call your state's Tech Act program. If the program in your state does not yet offer equipment exchange or recycling, you may still want to call them to discuss your need for such a program. And since equipment exchange and recycling is a relatively new concept, I would appreciate hearing about readers' experiences with these programs. **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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Macintosh Versus Windows

by Howard Shane

Q My nine-year-old son has learning disabilities and mild cerebral palsy. I want to buy a home computer. Should I get a Macintosh or a Windows-based computer?

A Until recently, we would have answered by saying that we had a strong preference for the Macintosh. However, as distinctions between platforms (types of computer) decrease—we have had to reevaluate that position.

The choice of computer platforms may be guided by a series of questions:

1. Which platform supports the specific software and adaptive hardware my child requires?
If your child needs specific software or adaptive equipment that works on only one platform, the question is resolved. However, if alternative solutions exist, the decision is not as easy.

In terms of general purpose and educational software, Windows has a huge advantage. However, the most interesting developments in adaptive software and peripherals were initially designed for the Macintosh, because multimedia features, such as synthesized speech, integration of graphics and animation, and ability to change text size, were built into the Macintosh operating system. Now, however, many Macintosh-based software and hardware developers are moving their products to Windows, as well.

Verdict: *Slight edge to Macintosh.*

2. Which is easier to learn?
The Macintosh is still the clear winner when it comes to removing the computer from the box, setting it up and getting it running. Both children and adults find it easier to learn.

Verdict: *Edge to Macintosh.*

3. Which platform is easier to use?
When things are running smoothly, both platforms are very easy to use; however, each has features that are preferable for specific needs. For example, Windows has always allowed the user to access menus and other functions through the keyboard, a benefit to individuals who cannot use a mouse. Windows 95 adds an excellent system for customizing the look and operation of the onscreen desktop, including cursor size and adaptive keyboard features. The Macintosh was first to offer some of these features, but Windows now implements them at least as well.

Macintosh has always offered a more consistent method of interacting with the computer; that is, commands learned for one program transfer readily to other programs. However, again, Windows is catching up.

It's still easier to install multimedia software on the Macintosh.

Verdict: *A draw.*

4. What kind of user support is available?
User support is extremely important for any computer system. However, we believe support is more important for a Windows machine, because most people find them more difficult to use.

Verdict: *Edge to Macintosh.*

5. Which gives more value?
In terms of computing muscle, a Windows-based machine provides more "bang for the buck." However, Macintosh prices have dropped, making the discrepancy in value much smaller. Again, it depends on the software your child needs, but even with multimedia software, the lowest priced Windows-based models are still generally less expensive.

Verdict: *Slight edge to Windows.*

6. My child uses a Macintosh at school. Should this affect my choice?
This depends primarily on your child's ability to learn and adapt to new environments. Some children do better with a consistent computer environment; for others, it makes no difference. If your child will be taking work back and forth between home and school on diskette, having the same type of computer in both places will offer some advantages, but it is not essential that the machines be identical. Additionally, should you encounter operating difficulties, computer experts at your child's school may be a support resource if you are using the same type of computer at home.

Verdict: *Slight edge to the type of computer used at school.*

Overall verdict

Consider the needs of other family members when making this expensive purchase, but put first the needs of those individuals whose software and hardware requirements are the most unusual. Regular computing needs of parents and siblings can be readily accommodated on either platform.

We haven't stopped recommending a Macintosh as the computer of choice, but our recommendation is no longer unqualified. **EP**

In this regular department, questions from readers are answered by staff members of the Communications Enhancement Center at Children's Hospital in Boston. The clinic is directed by Howard Shane, Ph.D., a speech and language pathologist and a member of the EXCEPTIONAL PARENT *Editorial Advisory Board. Assisting in the preparation of this month's column was Robert Follensbee, Ed.D., an educational technology specialist at the center.*

Since questions are answered without an interdisciplinary assessment, parents need to review any suggestions with appropriate professionals. Specific products are mentioned only to illustrate suggestions, not as endorsements.

Send questions to **Technology**. EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

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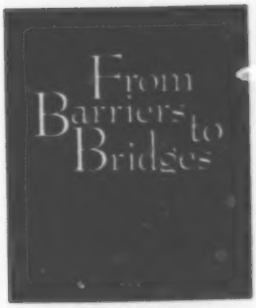
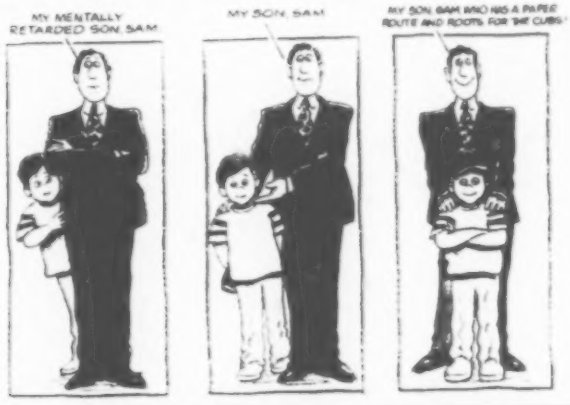


From Barriers to Bridges: A Community Action Guide for Congregations and People with Disabilities
edited by Ginny Thornburgh

FROM BARRIERS TO BRIDGES: A COMMUNITY ACTION GUIDE FOR CONGREGATIONS AND PEOPLE WITH DISABILITIES (National Organization on Disability) is available through Exceptional Parent Library, (800) 535-1910; $10; Item No. ND157OD.

From Barriers to Bridges is designed to foster dialogue between people with disabilities, their family members, religious leadership and the larger community. It provides the instruction needed to hold a "That All May Worship" conference and a wealth of other community-building activities.



From Barriers to Bridges, the third in a series of National Organization on Disability (NOD) Religion and Disability publications, includes personal stories and planning details from eight diverse "That All May Worship" conferences held in 1993 and 1994. "What is required is the remodeling of our minds and our hearts. A ramp is not enough," said one religious leader during the first conference.

The booklet, a 62-page guide to community action, includes interfaith prayers, poems, readings and songs; empowering stories; illustrations and an extensive list of community resources.

Ginny Thornburgh is the director of the Religion and Disability Program at NOD in Washington, D.C. Ginny's husband, Dick, has served as governor of Pennsylvania, attorney general of the United States and undersecretary-general of the United Nations. The Thornburghs have four grown sons, one with a disability, and five grandchildren.

Ginny is also the editor of LOVING JUSTICE: THE ADA AND THE RELIGIOUS COMMUNITY ($10; Item No. ND100OD) and THAT ALL MAY WORSHIP: AN INTERFAITH WELCOME TO PEOPLE WITH DISABILITIES ($10; Item No. ND084OD).

Include Us!

INCLUDE US! (Tiffhill Productions) is available through Exceptional Parent Library, (800) 535-1910; $19.95; Item No. LS158OD.

INCLUDE US!, a video for children of all ages, features young performers, some with disabilities, singing songs about inclusion. The songs are written by award-winning lyricist Lou Shaw, and the music is by Norman Sachs. Shaw and Sachs have written songs that allow young students to grasp the meaning of inclusion. The 33-minute video includes the following song titles: "School Daze," "Everybody's Different," "Getting There" and "Oh, What a Year We Had!" among others.

Mike Remus, president of The Arc writes, "I wish that every young student in America could see [this video] and grasp its meaning that children with and without disabilities can grow and learn together and have a good time in the process." The video has not only received kudos from The Arc but has also been honored with the Award of Excellence from the Film Advisory Board.

Frank Murphy, executive director of the National Down Syndrome Congress, hails *Include Us!* as "the first children's video with a proportionate number of children with disabilities... and so much fun that it will appeal to all children."

Disseminating Information on Children with Brain Injuries

How to educate parents and professionals outside traditional medical settings

by Marilyn Lash

What kinds of educational materials can best meet the needs of parents and professionals closely involved in the lives of children with brain injuries, and how should that information be presented? Those were the questions posed to parents, educators and physicians in a recent survey. The survey's emphasis was on products and programs that could benefit children and adolescents with traumatic brain injuries once they return home from the hospital.

One group surveyed were members of chapters of the Brain Injury Association (formerly called the National Head Injury Foundation), many of whom are parents. Another group participating in the survey was comprised of professionals from various disciplines, all of whom are members of the association's National Task Force on Children and Adolescents. Strikingly, both groups identified similar needs and priorities for products and programs.

Parents' needs

Those responding to the survey believed that parents must have access to written information on such subjects as brain injury and its consequences, methods of coping, strategies, resources for advocacy and special education. They wanted the information for parents to be presented in brochures, pamphlets and checklists, as well as in tip cards—short, user-friendly, practical summaries of tips on specific topics.

Regarding the most effective places for providing information, responses focused on medical settings—emergency departments, acute-care hospitals and inpatient rehabilitation programs.

What educators need to know

Basic education on the subjects of brain injury, learning styles and behaviors was the top need identified for educators. Respondents also recommended that educators have information on methods for identifying students and appropriate educational interventions. According to the survey, conferences and workshops are the best methods for providing educators with that information. Respondents also suggested that this information be supplied to educators on an ongoing basis, rather than only at the time a child's injury first occurs.

Information for clinicians

The survey results showed that pediatricians, emergency medical workers and family practitioners all need information on children with brain injuries, specifically on ways of identifying acquired brain injury and methods of early intervention. They also need to be made aware of the ways in which a brain injury may affect a child's ability to function in such areas as self-care, communication and walking. Other areas of concern include possible behavioral changes and the cognitive consequences of brain injury, namely, its effect on learning, attention and memory. Respondents suggested conferences, workshops, brochures, pamphlets, tip cards and checklists as effective ways to deliver information to clinicians.

A changing emphasis

Strikingly absent from the findings were responses indicating priorities and needs regarding the traditional medical model of rehabilitation—a hospital setting where answers to questions can be readily accessed.

Instead, respondents demonstrated a growing recognition of the importance of the outside community in the health care continuum. The survey indicated that family, school and community settings—the places where long-term rehabilitative services occur—need to receive increased attention. Likewise, written materials must be produced and packaged in ways that enable parents, educators and physicians outside hospital settings to obtain them conveniently and easily. **EP**

Marilyn Lash, M.S.W., is a researcher and training director at the Research and Training Center in Rehabilitation and Childhood Trauma of the New England Medical Center in Boston, Massachusetts.

This article was adapted with permission from REHAB UPDATE, a newsletter published by the Department of Physical Medicine and Rehabilitation of Tufts University School of Medicine and New England Medical Center. REHAB UPDATE reports on the work and activities of the Research and Training Center in Rehabilitation and Childhood Trauma, which is supported by the National Institute on Disability and Rehabilitation Research of the U.S. Department of Education, #H133B30044.

For information about REHAB UPDATE, write to: Publications Coordinator, Research and Training Center in Rehabilitation and Childhood Trauma, New England Medical Center, 750 Washington St., #75-K, Boston, MA 02111, or call (617) 636-5031.

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NEW PRODUCTS

BABY BACKUPS

Baby Backups are disposable changing pads designed to provide a convenient, sanitary changing surface wherever and whenever needed. Both sides of the pads are usable, either as a changing surface or for clean-up. Baby Backups come folded for convenient carrying and are available in packs of 2, 5 or 25.

Bright Ideas, Inc., Wichita, KS 67208-0714

Circle #294

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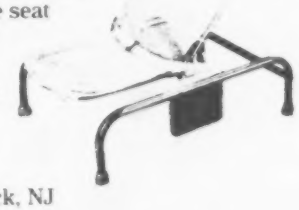

Maddak, Inc., Pequannock, NJ 07440-1993

Circle #295

TOUCHMATE

TouchMate can turn a regular computer monitor into a touch-sensitive screen. The TouchMate peripheral fits directly beneath the regular monitor and is secured to it by a universal fastener that eliminates the need for custom brackets.

TouchWare, touch-screen driver software for PC-compatibles, works with Windows, Windows 95, Windows NT, DOS and OS/2 operating systems.

MicroTouch Systems, Inc., Methuen, MA 01844

Circle #296

IMAGINATION EXPRESS DESTINATION: OCEAN

Destination: Ocean is a touch-screen-compatible CD-ROM that allows children to "explore" the ocean world around California's Channel Islands. Features include customizable audio, hand-painted ocean backgrounds, movie-making technology, text tools that allow users to place text anywhere on the screen and "Genius Stickers," characters that animate when dragged across the screen. The program runs on both Macintosh and Windows-based PC-compatible computers.

Edmark, Redmond, WA 98073-9721

Circle #297

DISCOVERY LIGHT BOX ILLUMINATED STORY BOOKS

The Discovery Light Box Illuminated Story Books reading system is designed for children with visual disabilities. Using a light box small enough for a child's lap or wheelchair tray, the books are specially bound so their transparent pages can pivot over the light box while remaining in order. Available titles include nursery rhymes, poetry and other children's favorites.

Light Bright Books, Durango, CO 81301

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KUSCH'KIN ACE

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Kuschall of America, Camarillo, CA 93012-8713

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 58) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319, (800) 227-0216 (V/TTY), (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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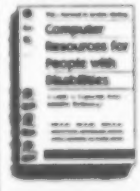

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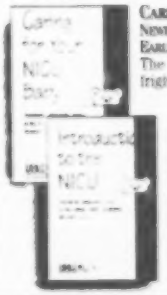

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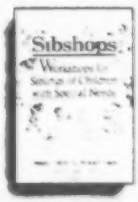

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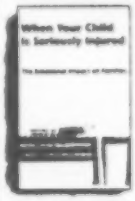

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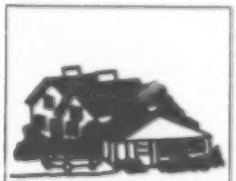

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My Life

by Christina Dockray

My name is Tina and I am 10 years old. I was born with a kind of muscular dystrophy. Some things are hard for me. I have a tracheostomy to breathe, and I wear leg splints. I lived in the hospital until I was five years old.

On August 10, 1990, I went to live with my "forever family." They adopted me. Now I have a mom, a dad, two sisters and a brother. We have a dog and three cats, too.

I go to school with my friends. We read and have circle time and art. In the summer, I go to day camp and take swimming lessons. My friends and I play softball. We have a lot of fun together.

Every year my family goes on vacation to Maine. I like the ocean. It is very cold.

My favorite hobbies are reading and watching videos. I read books every night. Barney and Lambchop are my favorite videos. **EP**

Six-year-old Tina (center) enjoys a 1991 Maine vacation with her "forever family," (from left) her mom, Bernadette; siblings, Karyn, Amy and Keith; and dad, Ken.

Christina Dockray, now 11, lives in West Milford, New Jersey, with her parents, Bernadette and Ken, and siblings, Keith, 19, Amy, 20, and Karyn, 21. Christina, a third-grader at the Apshawa School in West Milford, has congenital myotonic dystrophy and dyslexia. She dedicates her story "to my forever family."

Tina, 10, and nurse Judy Spence enjoy an autumn apple-picking expedition with Tina's class.

Batter up! Tina loves playing softball in a local girls league. "Although she uses a pinch runner," her mother explains, "she can bat and play the field. Someone has to stand behind her in case she loses her balance, but she does the rest by herself."

Mom's Turn:

I first met Tina when she was three years old. She was unable to walk, speak or sit independently. She had a tracheostomy and a feeding tube. Tina lived in the long-term care facility where I worked as a practical nurse. Over the next few years, our whole family fell in love with her.

When we first told people of our plans to adopt Tina, most thought we were a little crazy. We met many good, reasonable individuals who took it upon themselves to give us "advice"—like the doctor who said he didn't know "why anyone would want to adopt a child like that," and a fellow nurse who told me to go home to my "real children." Many medical professionals worried that our family, including Tina, had unrealistic expectations.

But by the age of five and a half, Tina, wearing leg splints and using a walker, began to walk. A year later, she joined a regular T-ball team and began swimming lessons. At the age of seven, she began attending a local elementary school.

Tina is a very important part of our family. She participates in all family activities, including her regular household chores. I can't imagine our lives without her.

—Bernadette Dockray

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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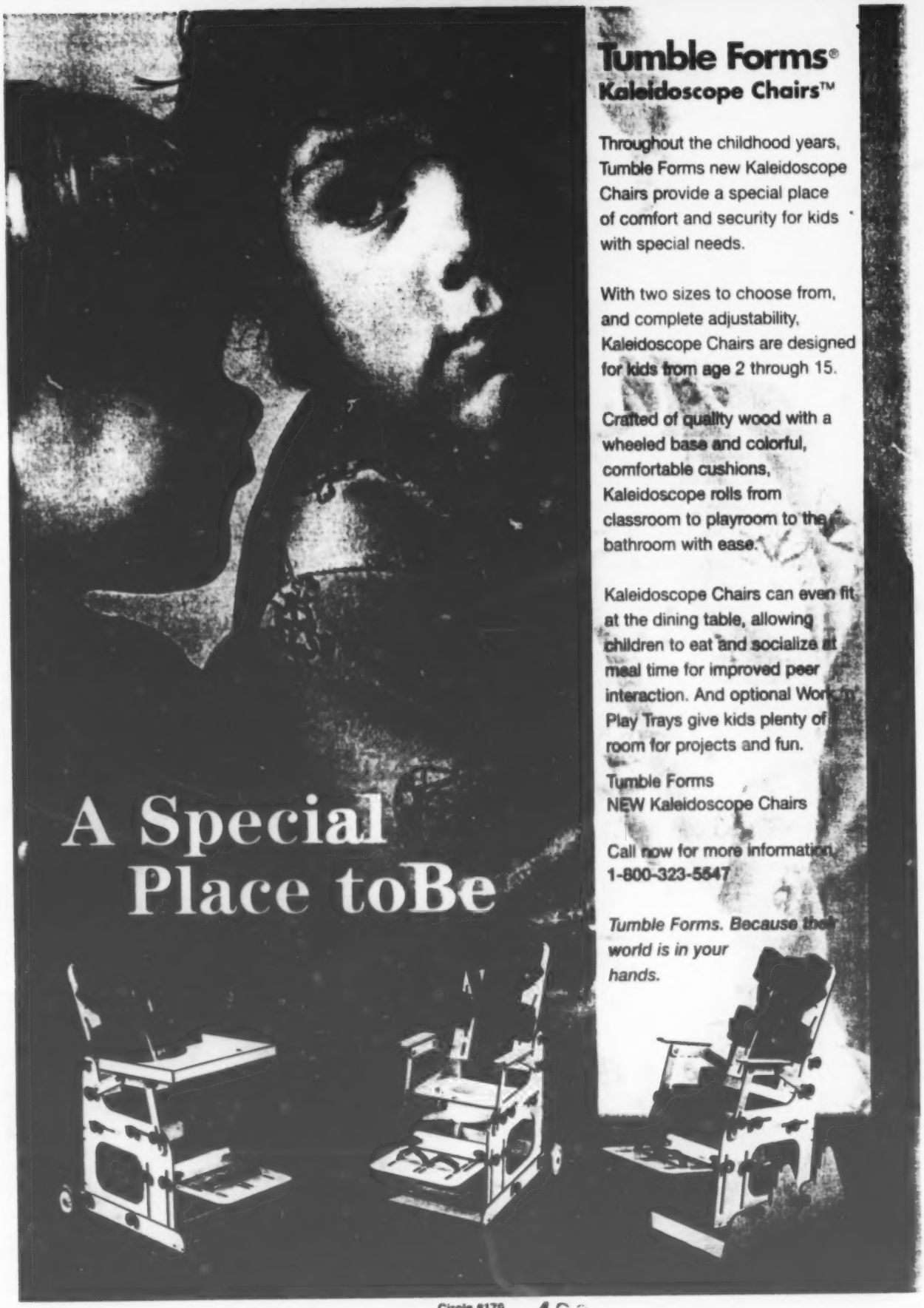

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The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since 1971

25th Anniversary Issue

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PUBLISHER'S LETTER

Happy 25th Anniversary, Exceptional Parent!

President John F. Kennedy once reminded us - - ever so eloquently - - that "We celebrate the past to awaken the future." In a sense, that is just what our June 25th Silver Anniversary Issue does.

As you read through the stories of this commemorative issue spanning the past twenty-five years, you cannot help but be filled with pride, admiration and appreciation for the tireless, unrelenting, passionate efforts of the pioneers who paved the way for those with disabilities. Accomplishments that 25 years ago would have been considered unrealistic are commonplace today! But these accomplishments would not have been possible without the efforts and dedication of people...ordinary people like you and me...working to accomplish extraordinary things!

When I was a young boy my father once told me, "Except in the eyes of God, all men are *not* created equal; so we are all responsible for helping those who cannot help themselves." He also told me that "Love is indestructible and, therefore, the most powerful human force." Today, those words ring loud and clear.

I am a fortunate man. I have a wonderful family: a loving, caring wife and five sons. One of my sons has a disability. For me Exceptional Parent was, is and always will be about hope when hope was seemingly forlorn. It is about inspiration and dreams. It is about *information that matters*, provided by *people who care*. It is about commitment, compassion and caring: the essential ingredients of love.

This, perhaps more than anything else, is what Exceptional Parent is all about: love. Love helps us keep a proper perspective and focus. Through love, we learn to look at the child first, the disability second. We learn to focus on what *can be done*, not *only* what cannot be done. When that happens, we begin to realize that all things are possible! Then we can more fully appreciate President Clinton's vision of challenging the 21st Century...the new millennium...with the strengths and talents of *all Americans*, the *able bodied* and the *differently abled* alike.

What a vision! What a way to awaken the future!

The next twenty-five years will be even better -- thanks to all of you!

Sincerely,

Joseph M. Valenzano, Jr.
President & Publisher

EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

JUNE 1996 VOL. 26, ISSUE 6

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EDITOR'S DESK

A Silver Anniversary Celebration!

We had ambitious plans for this special 25th anniversary issue: We hoped to convey a sense of history while providing a glimpse into a hopeful, exciting future. But most of all, we wanted to applaud you—our wonderful family of readers.

STANLEY D. KLEIN, PH.D., CIRCA 1971

◆ **We applaud parents.** From the start, EXCEPTIONAL PARENT's strength has been in the readiness of our readers to share their lives and their wisdom in these pages. For this special issue, we invited reader accounts that would capture the flavor of the wonderful, energizing relationships our readers have with the magazine. These personal accounts also illuminate the progress we have made—together—during this incredible 25-year journey.

◆ **We applaud organizations.** Over the years, many readers—parents as well as professionals—have commented on the magazine's unique ability to bring people together. From the very first issues, readers have found each other through these pages. We are especially proud of the role EXCEPTIONAL PARENT has played in the creation and evolution of many national organizations and are pleased to present several of their stories. We would love to hear from other organizations started as a result of connections made through the magazine; we are anxious to share more of these stories in upcoming issues.

◆ **We applaud children and young adults.** As part of our anniversary celebration, we invited organizations to help us identify 25 young men and women with disabilities who are already role models in their communities. The response was phenomenal! Suddenly, from all parts of the country, we started hearing about the unique contributions of so many young people, in all aspects of community life. Each of these stories demonstrates the ever-growing opportunities for individuals with disabilities to make a difference in their own lives and in the lives of others.

Stories like these were beyond imagination 25 years ago. Today, they are real—and we know there are many more. We invite readers to nominate additional young role models whose stories we can share in future months.

◆ **We applaud our leaders.** New laws and regulations have contributed to vast changes in opportunities for individuals with disabilities. But behind each legislative achievement is a story of individuals working together, individuals who found the time and energy to work for change. We invited two of these special individuals to help us look back at the foundation they helped establish for the advocacy efforts of the future: As a government official, Ed Martin worked year after year educating elected officials, guiding advocates and moving the system. And Julie Beckett is not only Katie Beckett's mom; she is also the mother of the "Katie Beckett waiver." Both stories offer sterling examples of the power of one caring person.

◆ **We applaud the media.** We know that media images of people with disabilities have the power to shape societal attitudes. As we look at progress in this arena, we are pleased to present articles from two places we all love to visit—*Mister Rogers' Neighborhood* and *Sesame Street*.

◆ **We applaud invention and creativity.** Ten-year-old Kevin Hatch dreams of a wheelchair with jet-powered engines that can fly and go on snow; Michael Gaglione, 18, wants "a rocket-powered megachair" with a "climate control unit" and "surround sound for a stereo system." As we smile, we remind ourselves that many of the mobility and communication devices that now make an enormous difference in the day-to-day lives of individuals with disabilities would have been equally unimaginable in 1971. We salute the last 25 years of innovation and look forward to an inventive future.

Thank you, Mr. President

President Clinton and former Senator Dole have honored us with their good wishes, as have Hillary Rodham Clinton, Ann Landers, Judy Heumann, Patricia McGill Smith and Dr. T. Berry Brazelton. We extend our thanks to each.

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Exceptional Parent magazine was founded in 1971 by Stanley D. Klein, Ph.D. and Maxwell J. Schleifer, Ph.D.

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BPA

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Circle #117

Child rearing is a vital and difficult task; unrecognized as such and unsung, perhaps, because it is so universal. Even more vital and much more difficult is the task of raising a child with a disability... Technical information stripped of professional jargon and practical advice on day-to-day care will share these pages with many special features, including ideas from our readers. Our goal is to help you to share with us the view that the child is our main concern; the disability, however severe, is secondary.

—"Statement of Editorial Purpose" June/July 1971

JUNE/JULY 1971

Parenting With Honesty and Openness

Learning and Sharing with EXCEPTIONAL PARENT

by Betty Pendler

In 1971, I took a course in special education because my daughter, Lisa, has Down syndrome. The professor asked me if I had ever written for EXCEPTIONAL PARENT because she had seen a letter in the magazine that she thought I might have written. "No," I replied. "I've never heard of it before." The professor's question and subsequent description of the magazine piqued my interest. But I didn't actually get to see the magazine until a few months later, when I first met editor in chief Stanley Klein at a conference in New York City. That was the beginning of a 25-year relationship with the magazine.

I had always enjoyed writing letters to the editors of various publications, and EXCEPTIONAL PARENT provided the perfect vehicle for me to agree, disagree and share my experiences. Eventually, I found myself in the position of being able to help parents of children younger than Lisa, who was then a teenager, by giving them concrete examples of the actions I had taken to improve our lives.

Empowering parents

The October/November 1971 issue of EXCEPTIONAL PARENT ran an editorial entitled "Parent Power." This editorial was one of the greatest influences on my life. Until that time, we parents were forced to abide by the attitude of society—that the professionals knew more than we did about bringing up our children. How much foresight EXCEPTIONAL PARENT had to suggest that parents are professionals in their own unique way, that their areas of expertise cut across many disciplines.

I remember copying that editorial and sending it everywhere—to public school officials, professional organizations and parent groups. It is my hope that many professionals read that article and, as a result, began to treat parents with more respect.

Betty Pendler, daughter Lisa and son Paul pose for a family picture at home while sharing tea and conversation with friends in 1991.

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It has taken a long time for parents to learn to use their power, but now, more and more parents are mobilizing to present their issues and concerns to those in positions of power. We are showing professionals and lawmakers that parents do indeed have power!

Speaking the unspoken

In another early EXCEPTIONAL PARENT article, a parent confessed to some very scary emotions regarding her child with Down syndrome—grief, trauma, anger, a death wish, an impulse to destroy—all of which I identified with immediately. This article made me realize I was not alone in having these emotions and hidden thoughts. This realization prompted me to speak up more often and more openly. I eventually submitted articles to EXCEPTIONAL PARENT to show other parents just how normal these feelings were. I realized that facing these emotions freed me to heal and move on.

I later became a well-known speaker on the subject of letting go. Based on my own experience, I helped other parents learn about how to move forward by letting go of those difficult feelings. When parents thanked me for opening up and sharing my experiences so honestly, I truly felt I had been of service to others.

Another difficult topic was the issue of sex and people with disabilities. As far back as July/August 1973, EXCEPTIONAL PARENT addressed this topic with an editorial stressing the need for knowledge and communication. This editorial was followed by many articles discussing all sides of the subject—including many by Sol Gordon, an expert on sex education, and by parents like myself. By printing these articles, EXCEPTIONAL PARENT almost forced parents and professionals to open a discussion about sex at a time when it was nearly unacceptable to do so. For many months, the magazine received an avalanche of letters on the subject—both pro and con—because what better place to air one's views than in EXCEPTIONAL PARENT?

Lisa Pendler, 17, is all smiles after a full day of fun at a recreation program for children and young adults with special needs sponsored by the New York City Parks Department in the summer of 1973.

Special values

EXCEPTIONAL PARENT provided me with affirmation in many of the choices I had made as a parent—for example, the way I'd handled sibling issues. From the time my son, Paul, was quite young, I had spoken to him openly about his sister. I encouraged his questions and gave him permission to have mixed feelings, just as I had. I told him that just as some people are born with one leg and can't walk, so Lisa was born with a smaller brain—but that she still was a wonderful sister. The more honest I was about my own feelings, the freer Paul felt to share his secret thoughts with me.

I found a television program that helped considerably—the story of a young boy and his dog, Lassie. On one episode, young Timmy asked his mother earnestly, "Can Lassie catch beavers?" to which she replied, "No." The boy had a crestfallen look on his face, so his mother went on to say that although the dog could not catch beavers, "Lassie has her own special values." I quickly caught on to that phrase and told Paul that Lisa was like Lassie—she might not speak as well as he did, but she had her own special values. At the time, however, I wasn't sure if Paul understood what I was trying to tell him.

That summer, my children attended a camp where Lisa was the only child with a disability. I overheard a little boy ask Paul, "Why does your sister talk funny?"

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Lisa Pendler (right, front) dances it up with her friend, Marcy (right, rear), and Marcy's sister (left) in 1992. Marcy and Lisa met and struck up a friendship while regularly taking the same bus several years ago.

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Paul replied firmly, "Because my sister is like Lassie; she has her own special values."

I shared this experience with many parents to demonstrate that being honest with children and giving them permission to talk about their secret thoughts is not easy, but that it really works.

The road to independence

When I read in EXCEPTIONAL PARENT about teaching children with disabilities to take the bus ("Public Transportation Training," June/July 1971), I decided to teach Lisa to ride the buses and trains in New York City. I realized it was vital for both of us that she learn to do more things on her own.

For many months, I accompanied Lisa and a friend on the buses and subway, pointing out the stops and the stations where they needed to change trains. The girls quickly learned to anticipate the two transfers they had to make. Finally, much to their glee and delight, I told them they were going to be on their own.

I used the travel training method endorsed by the New York City Board of Education—that is, on an individual's first "independent" trip, she is followed unawares by someone who can make sure that she makes the right stops. So, on the day of the girls' first solo journey, I borrowed a neighbor's large red coat—I never wore red—and a big hat. I followed the girls, furtively weaving in and out of the crowd so Lisa wouldn't see me. (Anyone watching could have easily reported me as a "strange" lady.) I got off the bus one stop before mine and rushed home, knowing I would arrive ahead of the girls because they were walking so slowly.

They finally walked in the door and exclaimed, "We made it!" I hugged them with congratulations.

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EXCEPTIONAL PARENT
Parenting Your Child or Young Adult With a Disability
The Magazine for Families and Professionals

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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They really did make it! And it became clear to me that my daughter was capable of more independence than I had thought. ("Children Learn While Parents Squirm," February 1977, tells the story in more detail.)

Moving on without guilt

My greatest challenge in seeking independence for both of my children was to think about the day when they would move out of the house. I looked forward to Paul leaving home to go to college, and I knew I should give Lisa a similar opportunity to spread her wings. I felt that those parents who put off making this decision did so more to assuage their own anxiety than out of love for their child.

As I read more and more EXCEPTIONAL PARENT articles by parents who had successfully dealt with this challenge, I began to visit various group homes with Lisa. I hoped to instill in her the desire to leave home; and call it brainwashing if you will, but it was Lisa who commented after three such visits, "I'm dying to get rid of my mother." Of course, this is a very normal sentiment for all children of a certain age, including those with disabilities.

Once Lisa actually moved to the group home, I must confess to being a bit miffed to see how quickly and positively she adjusted to her new surroundings—after all my years of self-sacrifice! But in reality, I was proud and pleased that she was happy and so capable of making this change. I began to write letters and give talks about the benefits Lisa and I both enjoyed from this happy, wholesome separation.

A new career

My relationship with EXCEPTIONAL PARENT ultimately led to a new career as a parent advocate—responding to letters from other parents and giving professionals and families the benefit of my many years of experience. Is it any wonder that I constantly sing EXCEPTIONAL PARENT's praises? **EP**

Betty Pendler is a member of the EXCEPTIONAL PARENT Editorial Advisory Board and the New York State Developmental Disabilities Planning Council. She is an active advocate for people with disabilities. Betty, the parent of a daughter with Down syndrome, has contributed numerous letters and articles to EXCEPTIONAL PARENT. She currently resides in New York City.

Circle #79

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Circle #109

A Survival Kit for Parents

by Ginny Thornburgh

(From left) Dick and Ginny Thornburgh with son Peter, 36.

I have always liked the image of "seasoned veterans." It implies staying power. My son and I have achieved this status by surviving decades of medical appointments, special education meetings, budget cut battles, vocational assessments and endless reviews by the Social Security Administration.

We have endured because the prize was worth it—a life of full dignity and participation for Peter. At age 36, Peter lives semi-independently in the community, takes a public bus to and from his job in the warehouse of a food bank, volunteers on Saturday in a greenhouse and works Wednesday nights with a reading tutor. In his words: "I like my work." "I like my boss." "I help poor people." "I like my church." "I want to go more places and do more things." "I like to go on trips."

Survival tools

One of the benefits that comes with being a more seasoned exceptional parent is the opportunity to pass on wisdom to mothers and fathers just beginning their journeys. Recently, a dear friend gave birth to a son with multiple disabilities. During her weekly telephone calls, I can identify with her roller coaster of disbelief, tragedy, exaltation and exhaustion. But because I have traveled much the same path, I can assure her and her husband of two things: first, that the fight for dignity and full opportunity for their son is worth every ounce of their energy; and second, that their strongest allies in battle will be other parents.

Are there lessons crossing disability lines that can be shared parent-to-parent? I believe there are. These lessons are more than casual ideas or thoughtful suggestions. They are, in fact, survival tools for parents once a child with a disability is theirs to love, nurture and raise.

• **Remember that you are your child's most important advocate.** You are the most valuable member of the team serving your child. You bring extensive knowledge and steadfast love. Unlike other team members, you are with your child seven days and nights a week, with no holidays. You must never permit others to treat you like a troublemaker, overprotective villain or nuisance.

• **Attend to your marriage and other supporting relationships.** During a meeting with special educators and therapists, a father questioned, "What is the most important thing I can do for my child?" The response was filled with wisdom: "Love her mother."

The realities and pressures faced by parents of children with disabilities are many and, at times, overwhelming—stress, isolation, feelings of inadequacy, financial worry, disappointment, pressure from family and, sometimes, guilt.

We can cope with those pressures by taking a break from parenting and attending to our own need for love, fun, peace and intellectual stimulation. Take a walk in the park. Go to a baseball

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Hats Off to Exceptional Parent

For almost 25 years, Exceptional Parent has been a source of information for my husband and me as we raised our son, Peter, who has a label of mental retardation.

A reliable magazine, like a trusted friend, can be counted on to stimulate and comfort, even inspire. A reliable magazine such as Exceptional Parent can be counted on to ease the long journey that lies ahead for those of us raising children with exceptional needs.

Recently, I have had the privilege of getting to know the editor in chief of Exceptional Parent, Stan Klein—a man of unusual competence and caring. Hats off to you, Stan, and to your superior staff on this your 25th anniversary.

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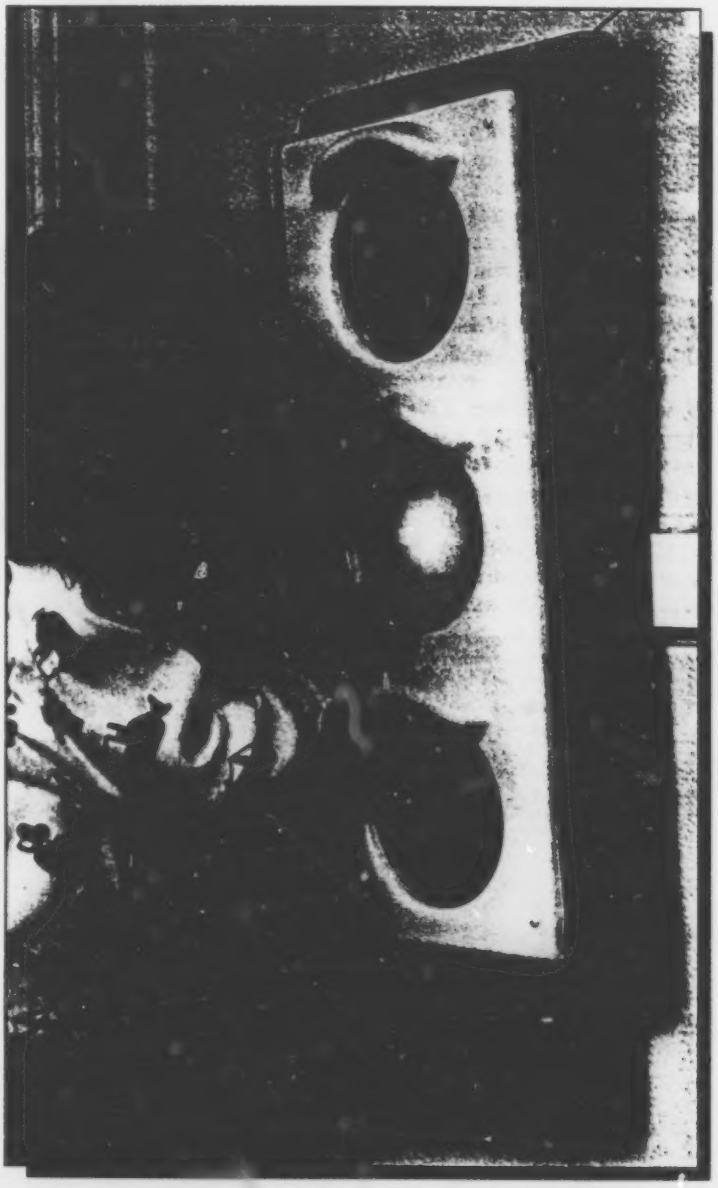

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Circle #119 494

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game. Plant a flower garden. Read a good book. Have lunch with a friend. Plan a respite weekend. This is also the time to turn to your faith community for support and hands-on assistance. If you are nurtured, it will be easier for you to nurture others.

• **Be informed.** This involves a lot of homework. Parents of children with disabilities need to know the law, know how education and other government services are delivered, and thoroughly understand health care and insurance benefits. You may want to use a tape recorder when important or especially complex information is being explained.

Before going into an important meeting, rehearse the key points you plan to make and prepare a written list of questions you intend to ask. And always bring someone along to strengthen you—a family member or friend, an advocate, a lawyer, or your minister, priest or rabbi. They will welcome this opportunity.

• **Find a support group of parents and other advocates.** Although you may often feel alone, you are not alone. Millions of parents struggle on behalf of their children who have physical, sensory or intellectual disabilities. It is both empowering and comforting to reach out beyond your own family to the company of other exceptional parents. This is the best place to exchange the names of competent doctors, dentists, therapists and babysitters, as well as stores that train their salespeople to care rather than stare. This is also a safe place to laugh and cry about the trials you are experiencing.

• **Train your child to be a self-advocate**. Exceptional parents have countless worries. Never far from our hearts are these prime concerns: How can my son or daughter live independently and safely in the community without me? What will happen when I die? One of the best ways to prepare for this day is to train our children for a life of full participation in the mainstream of society, to the greatest extent possible.

This training for independence must be coupled with the protection of self-advocacy, which teaches children and adults to stand up for themselves. It also fosters the communication skills necessary to express deep feelings, dreams and fears. Thus, self-advocacy training both protects and empowers. Our own son, Peter, through years of self-advocacy training, has said powerful things like: "I can do it by myself," "Leave me alone" and "When I next see you?"

Joys and struggles

As EXCEPTIONAL PARENT has always demonstrated, the particular joys and struggles experienced in raising a child with a disability are shared most easily with other exceptional parents. In this company, we are viewed not as superstars or martyrs but as mothers and fathers discovering our gifts while trying to be the best parents we can possibly be. **EP**

Ginny Thornburgh is the director of the Religion and Disability Program of the National Organization on Disability (NOD). The program is an interfaith effort encouraging congregations and communities to welcome children and adults with all types of disabilities. Ginny is the editor of THAT ALL MAY WORSHIP, LOVING JUSTICE *and* FROM BARRIERS TO BRIDGES, *NOD publications that are available through the Exceptional Parent Library. Ginny's husband, Dick, has served as governor of Pennsylvania, attorney general of the United States and undersecretary-general of the United Nations. The Thornburghs have four sons and five grandchildren.*

When Peter (shown here at age four) was an infant, he suffered extensive brain damage in an automobile accident.

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MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some ways you can give time a hand.

THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

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Circle #106

The Exceptional Contributions of EXCEPTIONAL PARENT

by James A. Autry

As a former magazine executive, I know that the best thing anyone can say about a magazine is not that people like to read it, but that people *need* to read it. It is this single distinction that makes all the difference for EXCEPTIONAL PARENT. We don't just want to read it, we *need* to read it. And we need it for several different reasons.

As parents of a 12-year-old son with autism, my wife and I have experienced the fears and frustrations all parents experience when they first learn "something is wrong." We know the pain of mourning the child who is never going to be.

We also know that after that pain must come celebration of the child who is. But I don't believe parents can make that transition alone; they require information, help, support and encouragement. They need to know that others are dealing with the same challenges, and they need to feel that there is a national voice for all parents in these situations.

Ronald Autry (front center) is surrounded by his family, (from left) brother Rick, sister-in-law Lyn, nephew Eric, and parents Jim Autry and Sally Pederson.

Ronald Autry, 12, and his cat, Jesse, enjoy the backyard scenery at their home in Des Moines, Iowa.

We constantly look to family, friends, associates and others in building a complex network of supporting relationships. But beyond our own communities and contacts, there must be other resources. High on our list of resources is EXCEPTIONAL PARENT. We all should be grateful to Stan Klein and his staff for the dedication and work it requires to keep such an excellent magazine coming to us, issue after issue.

EXCEPTIONAL PARENT serves its readers in four important ways:

• **Information:** It provides information on everything from research to practical applications in various areas of disability. It highlights personal stories and case histories as well as materials from professionals. It keeps us up-to-date on assistive technology and available resources.

• **Advocacy:** Through its content and through the staff's contacts, EXCEPTIONAL PARENT assures that lawmakers and policymakers are aware of the needs and desires of those of us in the "disability community." It also gives us information about how we can participate in advocacy efforts.

• **Networking:** EXCEPTIONAL PARENT may be the most effective networking resource we have. Through its articles and resources, through reporting on advocacy efforts and through personal stories, it keeps us in touch with one another.

• **Affirmation:** We need to hear that we are not alone; we need to hear that there is much to celebrate; we need to hear of endurance and success. If my wife and I could change the past, we probably wouldn't because we cherish all that Ronald is; but if we could change the future and what our son is up against, we would. And the truth is, we can. We can by focusing on every single day, because we know that what we do every single day is the best way to impact his future. But day-to-day life can be difficult sometimes; that's when we need to read other parents' stories and to be affirmed in what we are doing.

I am honored to contribute to this special anniversary issue of EXCEPTIONAL PARENT, and will end with just one statement: Thank God for this magazine. If it did not exist, somebody would have to invent it. **EP**

Former Fortune 500 executive James A. Autry is the author of four books, including the award-winning LOVE AND PROFIT. His business memoirs, IT TAKES A LIFETIME TO FIND WISDOM, will be published this fall.

Mr. Autry lives in Des Moines, Iowa, with his wife, Sally Pederson, and their 12-year-old son, Ronald, a fifth grader. Ms. Pederson is the former president of the Autism Society of Iowa and founder of The Homestead, a residential living and learning center for people with autism.

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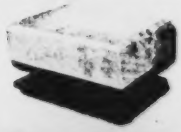

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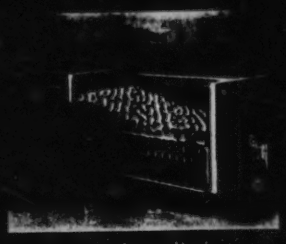

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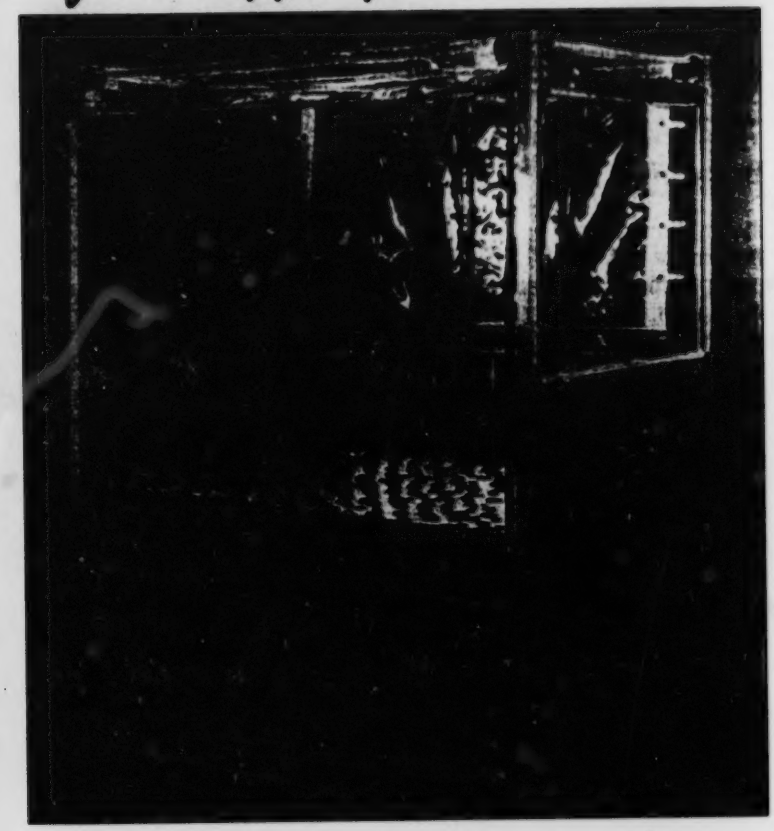

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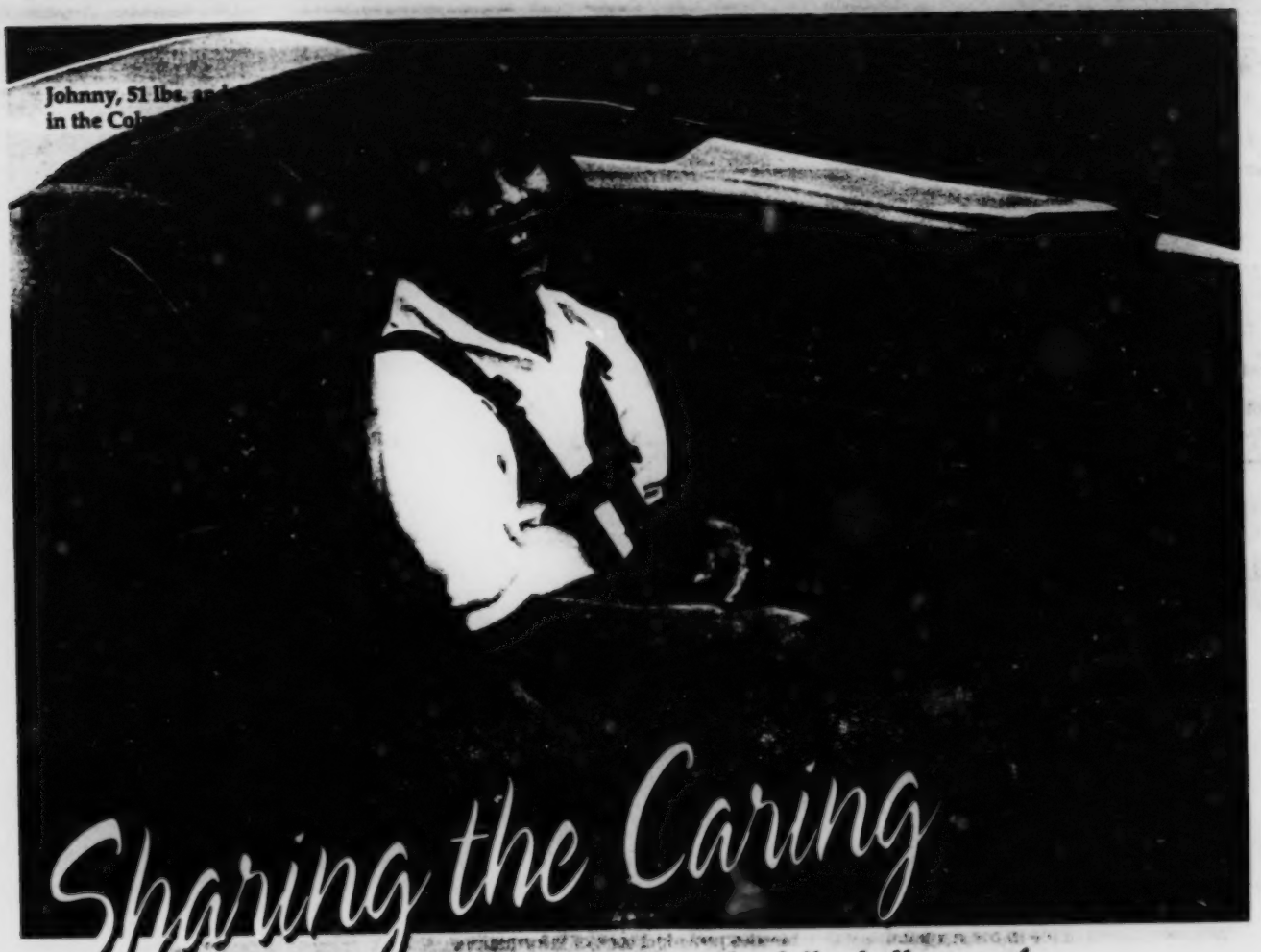

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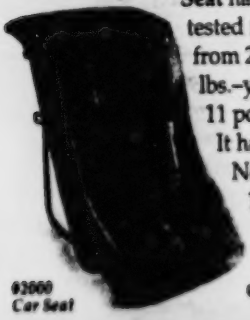

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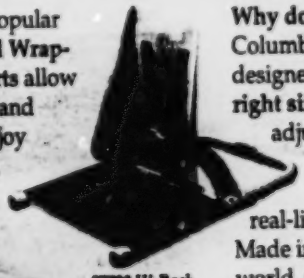

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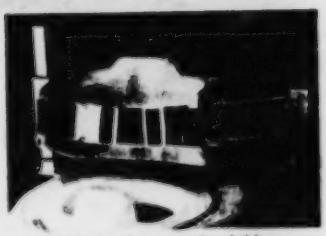

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Circle #96

Lauren Agoratus (right) and daughter, Stephanie, 2, enjoy the warm summer weather on their back porch.

Just See What You Started!

by Lauren Agoratus

My daughter, Stephanie, was born with renal agenesis, renal dysplasia, and grade IV bilateral vesicoureteral reflux—three serious kidney disorders. She spent her first two weeks of life in the neonatal intensive care unit on a respirator, heart monitor, feeding tube and intravenous tube. At first, the doctors didn't expect Stephanie to survive, but then they changed her prognosis: by the time Stephanie was six or seven years old, they said, she would have renal failure and possible mental and growth retardation. That's when I first subscribed to EXCEPTIONAL PARENT.

Initially, the doctors believed Stephanie would need surgery at three months. But as she progressed, they amended her prognosis to possible kidney failure at adolescence. Perhaps I was in denial, but, thinking all was well, I let my subscription to the magazine lapse. I figured I wouldn't need it anymore.

Eventually, however, it became clear that Stephane had some developmental delays in addition to her medical problems. When she hadn't learned to sit up by 13 months, we were referred to an early intervention program. I immediately felt an urgent need for information on physical, occupational and speech therapy, so I subscribed to EXCEPTIONAL PARENT again.

Besides providing tons of information, EXCEPTIONAL PARENT has given me a lot of support. There are no support groups in my area (although I am now starting one), so I've enjoyed reading letters and articles written by other parents. Many times, when I've felt overwhelmed, I've found other people in the pages of the magazine who are dealing with the same situation, or, in some cases, with even more complicated problems.

Three-year-old Stephanie loves to play outside.

I've also found a lot of information on health care reform and such current legislation as the reauthorization of the Individuals with Disabilities Education Act. Since the birth of my daughter, I've become an advocate for children with disabilities; EXCEPTIONAL PARENT is a valuable resource to me in this area as well. I am currently the New Jersey coordinator for Family Voices, a national advocacy group for children with special health care needs.

After I sent the magazine a child care resource list I thought might be helpful to other parents, Kim Schive, EXCEPTIONAL PARENT's associate editor, invited me to write what would be my first published article. I was very proud when "Help Wanted: Experience in Education or Health Care..." appeared in the February 1996 issue, but the real highlight was seeing Stephanie on the cover.

The response has been amazing! I have received phone calls, letters and comments from the heads of national and state organizations. I'm currently publishing articles in eight newsletters, four magazines and four anthologies, and making presentations to local social service organizations. Just see what you started, EXCEPTIONAL PARENT! **EP**

Lauren Agoratus lives with her husband, Steven, and daughter, Stephanie, in Allentown, New Jersey. She works as a customer service representative for Shaklee Corporation. Steven works in national and international medical equipment sales for the Urology Division of Convatech, a division of Bristol-Meyers-Squibb. Lauren is an active advocate for children with special needs, who has published articles in several publications and is working on a book.

501

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Circle #67

Growing with EXCEPTIONAL PARENT

by Julie Hettel

Julie Hettel (center), joins her family (clockwise from left), Mary, 7, husband Albert, Jr., Albert III, 12, Melinda, 9, and Jimmy, 2, in a 1994 family portrait.

My two favorite parenting magazines used to be *Parents* and *Growing Child*. Then, in August 1984, my daughter, Melinda, was born with Down syndrome. Suddenly, these once-reliable resources became very difficult to read and enjoy. In fact, I found them quite depressing. Every article reminded me of another milestone Melinda had not yet accomplished.

I read my first issue of EXCEPTIONAL PARENT at our local Easter Seals center while Melinda was receiving early intervention therapy. I remember having mixed feelings—thrilled to realize I was not alone, but, at the same time, very apprehensive as to the turn our lives had already taken. In any case, I subscribed right away.

I devoured each issue as soon as it arrived, and slowly the magazine worked its therapy on my soul. I read other people's stories, shared vicariously in their problems and successes, and felt renewed energy to move forward in acceptance and excitement about the places we, too, could go. I read about the newest developments in medicine, education, technology, therapy and equipment, feeling ever more capable of making the right decisions for Melinda. I learned of various resources available to our family and felt relieved to know there were places I could turn with my questions about everything from taxes, to estate planning, to the functions of many state and federal agencies. In short, EXCEPTIONAL PARENT made my job as parent to Melinda much easier, less stressful and more successful than would ever have been possible without it.

Mary Hettel (front, center), 5, and sister Melinda (rear, center), 6, go for a roller coaster spin at a local carnival in 1991.

Somewhere in the middle of all this learning, I gave birth to our second daughter with special needs. Mary, born in 1987, was diagnosed with cerebral palsy at the age of 12 months. Again, I found myself dealing with all those horrible emotions that go along with receiving an unexpected surprise. However, this time, they did not last as long. I believe it was because I felt better able to face the challenges at hand, due at least in part to the knowledge I had gained over the years by reading EXCEPTIONAL PARENT.

In the last few years, I have come full circle. At first, I knew very little about disabilities. Then, I read and learned as much as I could. Now, finally, I feel that I, too, have something to contribute to other parents, and to the professionals who work with our children. Yes, I can truly say I have grown with EXCEPTIONAL PARENT and, as a result, have become a better person and a better parent than I ever dreamed I could be. Thank you and happy 25th anniversary, EXCEPTIONAL PARENT! **EP**

Julie Hettel lives in Marseilles, Illinois, with her husband, Albert Jr., and four children: Albert III, 14; Melinda, 11; Mary, 9; and James, 4. Julie has been a special education teacher in the Ottowa Elementary District for the last 19 years.

503

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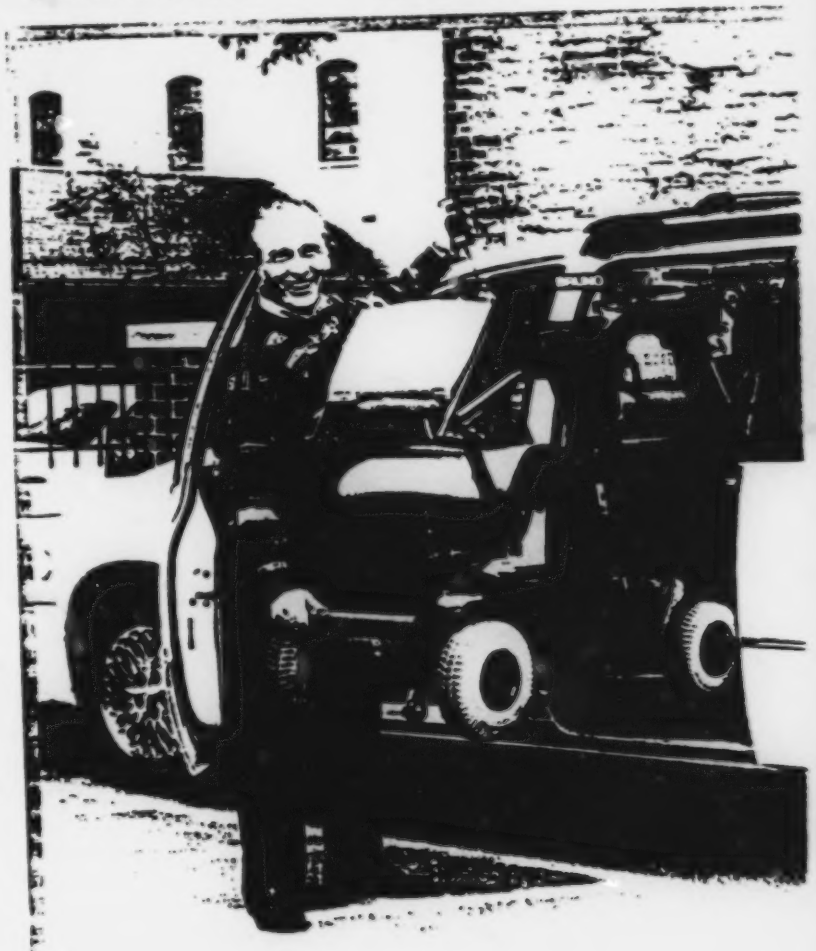

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Circle #93

Time After Time

by Carol Tingey

When I first got to know EXCEPTIONAL PARENT, the magazine was just getting started, but my life as the mother of a son with a disability was well under way—Jim was already a teenager. I thought I knew all about how to keep the tears from coming. I also thought I knew all about advocating for Jim's needs; after all, I had been successful in getting special education classes for him, even vocational training. My other four children were getting used to helping Jim and going slower for him. Jim could be so happy (see "Merry Christmas, Jim and a Happy Birthday," December 1977) and we were used to being with him.

Jim graduated from high school in 1978.

But I soon discovered that it is always the beginning because things always change. Soon, Jim was too old for school, and adult services were not available. He wouldn't be going to college, but he needed more schooling, adult friends and a job. I needed someone to talk to, somebody who would accept me, tears and all, somebody with whom I didn't have to pretend everything was fine (see "Things Are Worse Now," August 1980). The only "somebody" like that was EXCEPTIONAL PARENT.

Somehow, we kept going. Like his siblings, Jim wanted to move away when he finished high school. I began to hope he might be able to care for himself. He learned to earn money and to spend some of that money on himself. For example, he chose to go on several trips arranged for groups of adults with disabilities. (Not that it was always easy; one roommate stole his things, and another woke him up at night to tease him with a lit cigarette.)

Then, two years ago, the staff at Jim's group home stopped inviting me to meetings about Jim and his goals. Realizing that my son could not always advocate for himself, I started the process of becoming his legal guardian. His caseworker said I was "taking Jim's rights away" and berated me for not allowing Jim his "freedom." I tried to explain that one reason I had returned to school to study the needs of people with disabilities was to be able to help Jim, but the caseworker would not listen. When I hung up, I was in tears. How could this young man—younger than Jim, younger than *any* of my children—say things that would make me cry again? Eventually, I did become Jim's legal guardian. I am now consulted about disruptive roommates, wisdom teeth removal and job placement. I now realize Jim will always need this kind of help from me or from someone else who loves him.

Jim continues to charm people. When Jim goes to spend the weekend at the home of his younger brother, Neil, "Uncle Jim" is just one of the kids. (These weekend invitations thrill me, by the way. It doesn't seem that long ago that Neil was in high school telling his friends that Jim was adopted.) Jim's older brother, Dick, has a 16-year-old daughter who works in an after-school program for teens with developmental disabilities. Jim welcomes each new niece and nephew with joy.

Jim, now 39, enjoys spending a lazy weekend at the home of his brother, Neil (right).

I've learned by now not to claim that the tears are over, but only to say that whatever comes next, I can openly share with my "old friend," EXCEPTIONAL PARENT. I can tell it like it is and be honest about how it feels. And isn't that what friends are for? **EP**

Carol Tingey, Ph.D., lives in Midvale, Utah, and works as a psychologist in the rehabilitation unit at the University of Utah Hospital. Carol, a member of EXCEPTIONAL PARENT's Editorial Advisory Board since the late 1970's, published her first article in the February/March 1972 issue ("Why Can't Johnny Look Nice, Too?"); since then, she's published more than 10 additional articles in the magazine. Carol has five grown children—Dick, Blaine, Jim, Neil and Trish—and is shown here with her newest grandchild, number 15.

505

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506

Circle #103

When parents learn that their child has a handicapping condition, they may want to talk to someone who understands how they feel... Parents often say, "If there only had been someone there in the beginning who had gone through a similar experience, who could have given us hope..." Parents can benefit and be comforted by the knowledge that other families have faced similar crises and have managed to cope...

—"Parent to Parent Support" by Sue Scott and Phyllis Doyle June 1976

OCTOBER 1989

EXCEPTIONAL PARENT has always had a unique capacity to bring people together in new and powerful ways. This is especially evident in that section of the magazine now called *Search & Respond*—letters to and from parents and professionals seeking information, connections and support from others. Connections made through these pages have led to close friendships and more. We are especially proud of our role in the creation and evolution of many national organizations for specific disabilities and are pleased to present several of their stories in the pages that follow.

Never Again Alone or Uninformed

by Gwyn Rogers

Our sixth child, Daniel, was born in 1979. He weighed nearly ten pounds and had numerous medical problems. The doctors initially diagnosed him with "FLK syndrome"—which I later learned stood for "funny-looking kid." My husband, Charles, and I thought Daniel was beautiful. One pediatric neurologist told us Daniel would never walk or talk; he advised us just to take him home and love him. Another specialist advised placing him in an institution.

After months of tests, geneticists finally diagnosed nine-month-old Daniel with Sotos syndrome (also called cerebral gigantism). Although no blood test, chromosomal study or brain scan can positively identify the condition, young children with Sotos syndrome are known to have developmental delays and a number of unique physical characteristics, including rapid growth, often with advanced bone age. Children with Sotos syndrome also have characteristic craniofacial features, including a large head with a tall, narrow skull; a high, arched palate; wide-set, down-slanting eyes; a flat nasal bridge; thin hair; a prominent forehead and a "receding" hairline.

After receiving the diagnosis, I went home and cried. In a way, having a name for Daniel's condition made it feel definite that my child had special needs. I was desperate to help him learn and grow, but I didn't know where to start.

I began by contacting the doctor who

The Rogers family has grown over the years, and now includes (clockwise from top left) son Joe, son-in-law Chris Covey, Charles, Gwyn, Daniel, daugher Elizabeth Covert, son-in-law Mike Covert, son Ben, daughter Debbie, daughter Kathy Covey and daughter-in-law Juanita.

had first described the condition in 1964 and for whom the syndrome is named. He concurred with Daniel's diagnosis but was unable to offer additional information about the condition or available support groups. (In fact, 10 years later, and six years after our support group was founded, I received a letter from this doctor asking *me* for literature about the condition!)

As my every attempt to learn more about Sotos syndrome failed, I became increasingly frustrated. After five years of feeling alone with our challenges, I wrote a *Search* letter that was published in the December 1985 issue of EXCEPTIONAL PARENT. My letter said I would like to form a support group and would love to hear from other families dealing with Sotos syndrome. That *Search* letter brought 21 replies!

In 1986, I began sending out a newsletter. Two years later, we incorporated the Sotos Syndrome Support Association as a nonprofit organization and held our first national conference, now an annual event. By 1991, we had 121 members; today we have more than 250. We have a handbook and brochure available for families of newly diagnosed children. (I would have paid thousands of dollars for those items when Daniel was first diagnosed!)

As the organization grew and I became busier with my teaching career, I reluctantly stepped down from organization contact person to secretary, then board member, and then 1993 conference co-chairperson. Now, I'm just a regular member and the always proud mother of Daniel, now a 16-year-old high school honor roll student (see page 49).

I am so very thankful to EXCEPTIONAL PARENT for helping us provide a forum where families dealing with Sotos syndrome can join together for mutual support and education. Thanks to EXCEPTIONAL PARENT, a Sotos family need never be alone or uninformed again. You have our eternal gratitude. **EP**

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"We Can't Have the Only Child Like This!"

by Ruth Anderson

Eight and a half years ago, my husband, Mike, and I had a beautiful baby girl. We named her Crystal. By nine months of age, it was clear Crystal was not reaching typical developmental milestones.

Soon Crystal was receiving many different therapies from many types of professionals. One day, I added up their combined years of experience; it was well over 100 years! Yet when I asked if they had ever seen another baby like Crystal, they would say, "Nope, she sure is a puzzle."

Ruth Anderson (left) shares a tender moment with daughter Crystal, 8. "Crystal continues to make slow, steady progress," says Ruth. "She attends a local elementary school, where she is integrated into regular classes as much as possible. She is the light of our life."

Crystal's wonderful physical therapist, Roni Rummel, had worked with infants for more than 15 years. She was very knowledgeable about babies and the service system, and I pestered her for information at every therapy session. When I asked her what I should be reading about disabilities, Roni replied, "You need to get a wonderful magazine called EXCEPTIONAL PARENT."

Roni gave me a copy of the magazine, which I read and re-read until it was dog-eared. When my own subscription finally started, I waited eagerly for each issue and read it cover to cover—always starting with *Search*. But I never saw a letter describing anything like my little "puzzle."

When Crystal was two, Roni said it was time to do an MRI (magnetic resonance imaging) of Crystal's brain, in hopes of finding the reason for all her delays. The MRI showed hypomyelination, sometimes called delayed myelination or incomplete myelin. Myelin is the substance that insulates the pathways through which messages are transmitted within the brain and the rest of the central nervous system. If an individual doesn't have enough myelin, the messages do not transmit

continued on page 28

508

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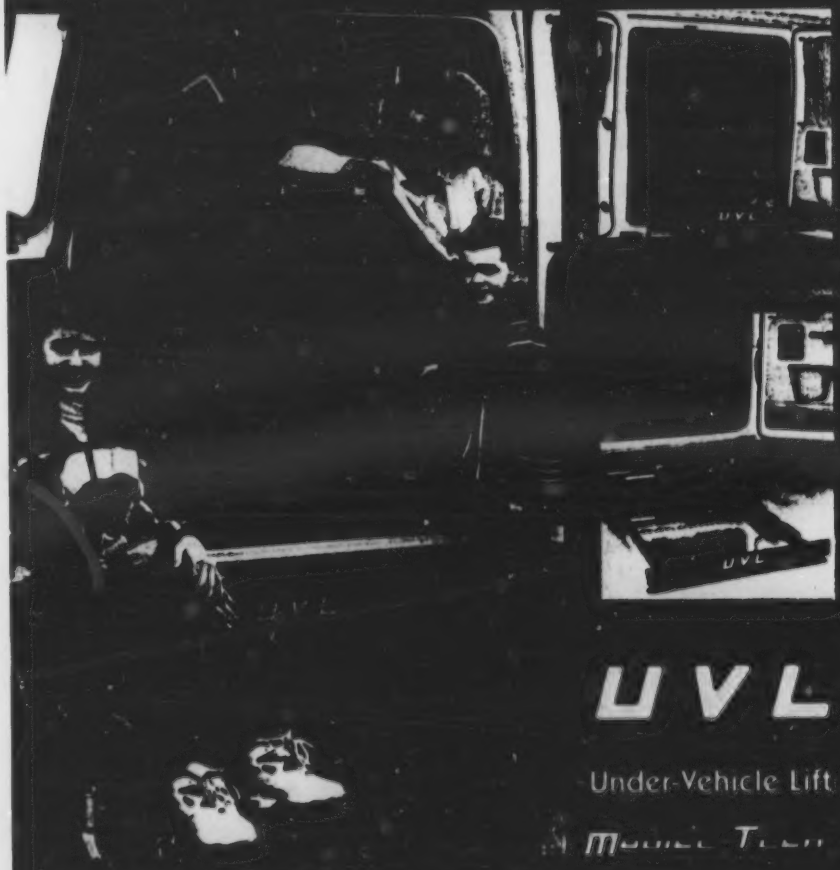

Circle #61

continued from page 27

correctly. The consequence is global developmental delays.

I had spent two years devouring every issue of EXCEPTIONAL PARENT without seeing a *Search* letter that described anything like our child, so I decided to write one myself. I told my husband, "You and I are not unique enough to have created the only child like this in the world! There must be others, and I am going to find them."

Within two weeks of my *Search* letter's publication, I had received 15 letters from parents of children just like Crystal. None of them had ever had any contact with another family like their own. I realized that for the purposes of networking and future research, I had to start a newsletter. So I started producing the *Myelin Messenger*—on my kitchen table, using an antique typewriter.

Today, that newsletter goes out to more than 100 parents throughout the United States and Canada, a number that increases with each issue. For the first time, parents of children with insufficient myelin have a resource, a connection meant especially for them. Clinics, agencies, children's hospitals and universities constantly refer grateful parents to us. And recently, some researchers have said that individuals with hypomyelination may be ideal candidates for cell transplantation experiments.

We've come a long way from "No one has ever seen a child like this," and none of it would have been possible without one exceptional resource—EXCEPTIONAL PARENT magazine. **EP**

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It Started with a Postage Stamp...

by Kaye McSpadden

Eighty-seven people attended the Lowe Syndrome Association's fourth international conference held in Downers Grove, Illinois, in 1993—21 were boys with Lowe syndrome.

When members of the Lowe Syndrome Association (LSA) opened a recent issue of the organization's newsletter, *On the Beam*, they were greeted with a dramatic announcement. Researchers had discovered the function of the gene that causes Lowe syndrome (also known as oculo-cerebro-renal syndrome), a rare genetic condition occurring only in males. Features of the condition include congenital cataracts, poor muscle tone, mental retardation, short stature and renal tubular acidosis (a kidney disorder).

The discovery that this rare syndrome is caused by an enzyme deficiency brought hope to LSA's 150 member families in the United States and eight other nations—hope that was only a dream 15 years ago when the organization was born.

It all began with a *Search* letter published in the October 1981 issue of EXCEPTIONAL PARENT. My then three-year-old son had Lowe syndrome, and I wanted to contact other families who had children with the condition. At the time, very little was known about the syndrome, and I had never seen

continued on page 30

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continued from page 29

another affected child. Doctors answered most of my questions by saying, "We just don't know."

After my letter appeared, six families from around the country contacted me. We soon found we had so much to share with each other that we needed a newsletter. Our efforts to find still more families paid off, and by 1986, when the group formally incorporated, we had 61 member families. That same year, we held our first international conference, an historic occasion that brought many parents together face-to-face, for the first time.

In the next few years, LSA members began working closely with researchers, providing them with needed tissue samples as well as financial support. Through newsletters, booklets and other materials, we worked hard to provide the best possible information to families and professionals. With generous donations from supporters, the organization's annual budget grew from a few hundred dollars to more than $20,000.

In recent years, the organization has benefited from the involvement of even more active members, a welcome change from the days when my job title might have been president/treasurer/secretary/publicist/newsletter editor. Nevertheless, LSA's dedicated all-volunteer leadership continues to face the challenge of trying to achieve its goals despite the distances that separate us. Recently, we have been investigating ways of facilitating communication and operations through the Internet.

This summer, LSA will hold its fifth international conference. Once again, parents, friends and professionals will gather to share a weekend together. Doctors and scientists will explain the latest research discoveries and answer parents' questions about their children's care. Family members will build friendships and offer each other understanding and support. Parents will go home empowered with new knowledge and encouraged with the assurance that they are not alone.

And it all started with a postage stamp 15 years ago. **EP**

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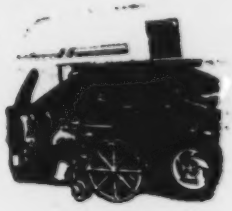

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Special Friends

by Becky Richardson

The Richardsons (clockwise from left): Tom, Becky, Alan, Patrick and Craig.

The support group for the chromosomal disorder known as 4p- or Wolf-Hirschhorn syndrome began with my *Search* letter in the February 1985 issue of EXCEPTIONAL PARENT. Our son, Craig, was three years old, and although we knew his chromosomal deletion was a rare one, we also knew he couldn't be the only one.

That *Search* letter produced seven or eight initial responses. Because so little was known about the syndrome, my first initiative was to set up an information exchange. I asked each family to submit a biography of their affected child in exchange for receiving biographies of other children. From those biographies, we learned about the developmental histories of other children. Sometimes those histories proved medically valuable as the experiences of others alerted "newer" parents that their children were at risk of developing seizure disorders, curvature of the spine and eye disease.

The biographies also provided feelings of connection and hope. Parents discovered that other children with the syndrome also love mirrors, mylar balloons, music and motion. They learned that some children *do* learn to walk, some *can* be toilet trained and even those with the most limited skills respond to love, enjoy rough-housing and unfailingly give back the gift of a smile.

In the last 11 years, that once short list of families has grown into a tremendous network. Brenda Grimmet, a mother in Ohio, started a newsletter that is now published several times a

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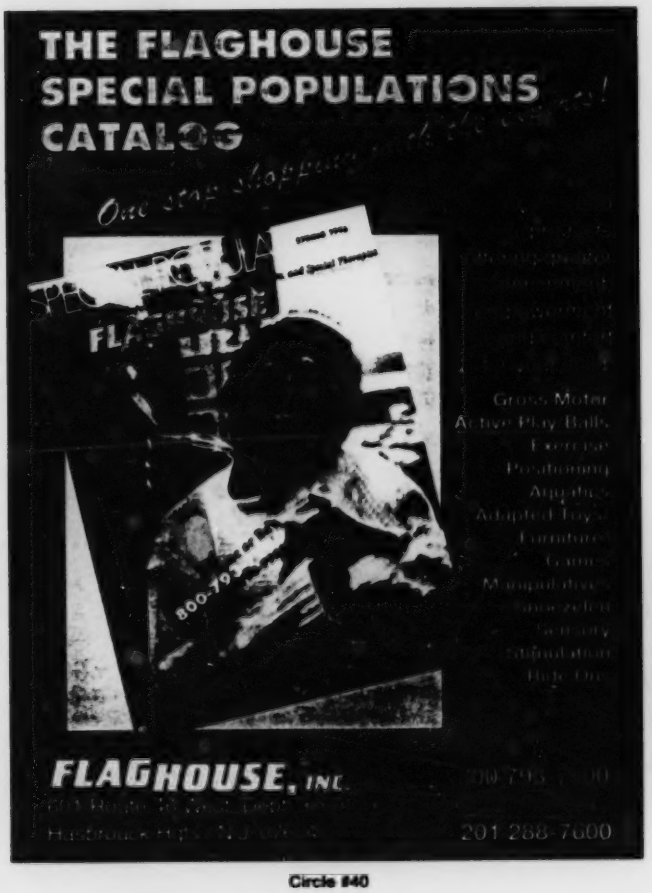

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Circle #105 514

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year. In 1992, another mother, Valerie Dillavou-Rivas, bravely volunteered to coordinate a national gathering of Wolf-Hirschhorn families in Des Moines, Iowa. About 25 families attended. The second Wolf-Hirschhorn "family reunion," held in Asheville, North Carolina, in 1994, drew families from as far away as California, Canada and Germany (see "Is This Going to be Sad?" January 1995). Our next reunion is planned for July 1996 in San Francisco.

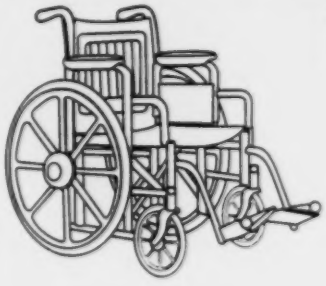
The group now numbers 230 families with children ranging in age from infancy to 30 years old. We are all learning as we go and have discovered that other parents are often the best source of information. Unfortunately, the medical literature on this condition is very outdated and fails to offer the things we need most—coping strategies and hope for the future.

I often compare our situation to that of the parents of children with Down syndrome who began organizing in the 1950's. Today, medical professionals view 4p- syndrome much like they viewed Down syndrome back then. During the last 40 years, parents of children with Down syndrome have worked hard to change those negative attitudes; now, many medical professionals, as well as the general public, realize the potential of children with Down syndrome. We, too, hope to change attitudes toward 4p- syndrome.

Putting families in touch with each other and watching them discover that inevitable bond is the reward I am constantly being given for my efforts in starting the support group. The saying, "Friends divide the grief and multiply the joy," applies to the special friends we have acquired through our involvement with the group.

Over the years, EXCEPTIONAL PARENT has been a major resource, first by supporting our efforts to start the support group, and then by helping us familiarize professionals with this syndrome. In addition, many articles published in the magazine have been enriching and enlightening in our learn-as-we-go approach to life with our kids. For all you provide, EXCEPTIONAL PARENT, you, too, are one of our special friends. **EP**

FOR MORE INFORMATION:
4p- Parent Network
c/o Becky & Tom Richardson
2048 South 182nd Cir.
Omaha , NE 68130
(402) 330-7135



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Making a Rare Disorder Seem a Little Less Rare

by Joan Mowery

My daughter, Michele, was diagnosed with Shwachman syndrome when she was three years old. Shwachman syndrome, a rare multi-organ disorder, primarily affects the pancreas, bone marrow and skeleton. Due to insufficient digestive enzymes for the absorption of nutrients, individuals with Shwachman syndrome are small and often have bone abnormalities; because of low white blood cell counts, they suffer frequent, life-threatening respiratory and skin infections. As many as 25 percent of affected children die during infancy or childhood.

Joan Mowery started a support group for parents of children with Shwachman syndrome when her daughter, Michele, was 31 years old.

But my daughter was a fighter and a survivor. In 1994, when Shwachman Syndrome Support was founded, Michele was 31 years old. And after 28 years of coping with a rare disorder, I realized that families and doctors knew no more about this condition than they had at the time of Michele's diagnosis. With the encouragement of one of Michele's physicians, Dr. Allen Dozor, I set out to establish a support organization that could channel the collective talents and energies of parents and professionals.

Dr. Dozor and I began by sending letters to a number of other physicians and three medical journals. This effort led us to a few other families. Next, I contacted NORD (National Organization for Rare Disorders) and MUMS (Mothers United for Moral Support), both of whom helped me identify several more families. Still more families contacted us following the publication of a *Search* letter in EXCEPTIONAL PARENT magazine.

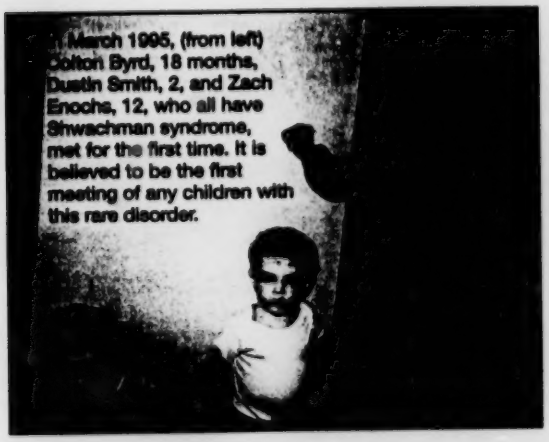
Just two years later, our group's membership has soared to more than 100 families and continues to increase rapidly. Our six board members, located throughout the United States and Canada, rely on e-mail to conduct the group's business. This technology dramatically enhances the ease and speed with which we can handle any issue that arises. Many members also communicate with each other by e-mail. Our Web site has introduced the group to new members from all over the world, including The Netherlands, Italy, Great Britain and Australia.

The group's first priority has always been to link families for mutual support. Since Shwachman syndrome can affect different organ systems in different individuals, new members are asked to complete a brief questionnaire that allows us to put them in touch with families who have similar health concerns.

As with most rare diseases, lack of information has been a frustration to many families coping with Shwachman syndrome. Shwachman Syndrome Support has attempted to fill that void through the development of various educational materials. We also publish a quarterly newsletter containing organizational updates, stories from parents and articles by medical professionals about treatment and research.

Yet another priority is advocating for research and notifying members of opportunities to participate in worthwhile research projects. For example, an ongoing study conducted by Dr. Peter Durie at The Hospital for Sick Children in Toronto, aims to discover the gene responsible for this disorder.

We have no shortage of talent among support group members, and their talents are matched only by their enthusiasm and willingness to pitch in and help where needed. Shwachman syndrome is still a rare disorder, but in the last two years, Shwachman Syndrome Support has made it seem a little less rare and frightening to many families all around the world. **EP**



In March 1995, (from left) Colton Byrd, 18 months, Dustin Smith, 2, and Zach Enochs, 12, who all have Shwachman syndrome, met for the first time. It is believed to be the first meeting of any children with this rare disorder.

FOR MORE INFORMATION:
Shwachman Syndrome Support
c/o Joan Mowery
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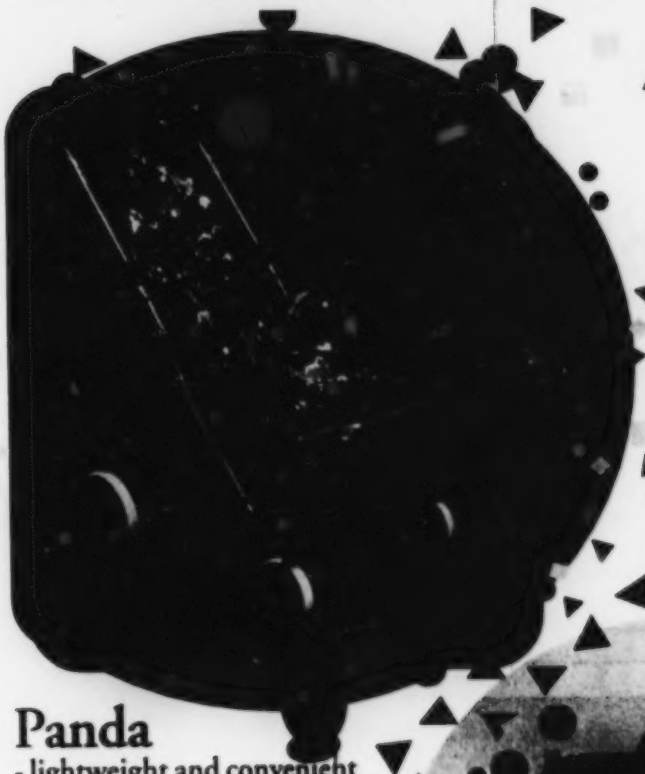

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EXCEPTIONAL PARENT MAGAZINE

25th Anniversary

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Congratulations to Stan Klein and the staff at EXCEPTIONAL PARENT on your 25th anniversary. What a 25 years for children with disabilities—vast improvements in education, technology, and expectations! EXCEPTIONAL PARENT has been there all the way—educating and inspiring. EXCEPTIONAL PARENT is certainly well-named—because being a parent with a child with a disability is often a demanding challenge. Every issue of EXCEPTIONAL PARENT is carefully read in my office, and I know that EXCEPTIONAL PARENT is essential reading for parents and professionals interested in children with disabilities.

Good luck over the next 25 years.

Bob Dole

THE WHITE HOUSE

WASHINGTON

Congratulations to the staff and supporters of EXCEPTIONAL PARENT magazine as you celebrate your twenty-fifth anniversary in print.

For more than two decades, your magazine has provided consistent and informative reporting, giving help and hope to parents who face the daily challenges of raising children with disabilities or special health care needs. Each of you can be proud of your role in producing such a successful publication. You've earned the trust and respect of your readership, and on behalf of all those who have benefited from your vision and commitment, I commend you on a job well done.

Best wishes for much continued success.

Bill Clinton

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Giving Each Child A Chance

by Hillary Rodham Clinton

First Lady Hillary Rodham Clinton and U.S. Attorney General Janet Reno greet a class of deaf children at Drew Elementary School in Miami, Florida, on December 9, 1994. Clinton and the children are signing, "I love you." Photo: Sharon Farmer, White House Photos.

Good friends of mine in Arkansas have an adopted daughter from Thailand. Nine-year-old Kate was born without arms. Soon after she arrived in America, Kate and her family came to the White House to visit us. She spoke little English, but she was very precocious. One day, she found a videotape of the White House and placed it in the VCR with her feet. When the Lincoln Bedroom, where she had been sleeping, came on the screen, Kate pointed to it and said, "My room! My room!"

After spending time with Kate, you begin to focus on what she can do, not what she can't. I believe that is the way each of us should treat all children with disabilities. Kate gets A's and B's at school; she is a whiz on the computer and a valuable member of her softball team—she holds the bat between her chin and her shoulder and has had a base hit at every game this spring. This summer, Kate and her two older siblings will attend camp together. "It's just been an amazing joyful experience for us," their mother says.

The President believes that this country cannot afford to waste any of our children. Each child is a gift from God, capable of making great contributions to their families and to our society. As I discuss in my book, *It Takes a Village*, each of us has the opportunity to make sure every child is given the chance to live up to his or her potential.

While we, as parents, have the primary responsibility for raising our children and providing them with opportunities, we cannot do it alone. We all need the support of families, religious organizations, schools, businesses, employers and government to become the best parents we can and to make sure no child is labeled "hopeless" or "ineducable."

Although it took many years, our country is now beginning to recognize the important role people with disabilities can play in all sectors of our society. Through the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act (ADA), our society empowers citizens with disabilities of all ages to lead fulfilling, productive and happy lives. As recently as 20 years ago, many children with disabilities were not allowed to attend local public schools with their peers. But today, they are learning to read and write in classrooms throughout every state of the union.

These changes came about because of parents who never gave up on their own children and who channeled their unconditional love into advocacy for all children. But these accomplishments need to be defended vigorously. The President and his administration are committed to enforcing and preserving the rights of all citizens, including those with disabilities. We have already witnessed efforts to undermine Medicaid in recent months and we must ensure that the IDEA's strong protections for children with disabilities are not weakened. That is why we all must be vigilant, keep our voices loud and clear, and make everyone—politicians, coworkers, friends—understand that a humane, democratic society like ours cannot abandon hope for any of our citizens. We are all part of the same human family.

Hillary Rodham Clinton is the country's First Lady. Mrs. Clinton, a well-known advocate for children, lives in Washington, D.C., with her husband, President Bill Clinton, and daughter, Chelsea, 16.

Convaid Products

A family business celebrates 20 years

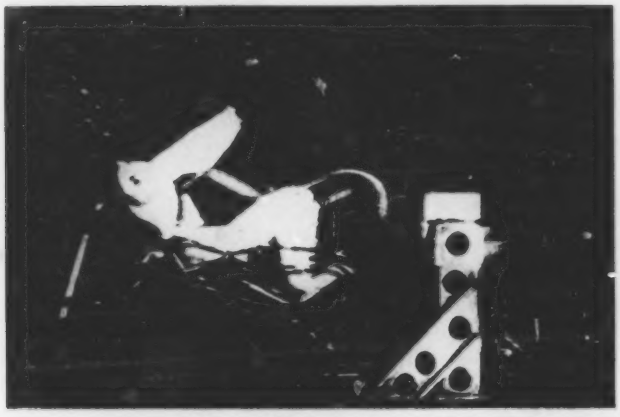
Twenty years ago, Rachel Watkins, an occupational therapist who'd had extensive experience with California Children's Services, explained to her husband, Merv, that her young clients with disabilities needed a special stroller—one providing custom positioning and adjustment for growth, while remaining as lightweight and collapsible as a traditional umbrella stroller.

Merv Watkins, an engineer, was able to design and patent just such a chair: a unique, folding stroller that used the child's weight to open the stroller wider and maintained its fabric tautness, even over time.

With the success of this new stroller, Merv and his family began Convaid Products in Palos Verdes, California. Merv's 12-year-old son, Nathan, helped assemble the chairs. Nathan, still working at Convaid, is now the vice president of manufacturing.

The development of the Cruiser

The following years saw dramatic improvements in Merv's original stroller, known today as the Cruiser. The company added many different positioning accessories, which fold with the chair, to provide the positioning options therapists need for their clients.



In 1991, Convaid learned that many children were being transported on school buses while seated in Cruiser strollers. This realization led the company to embark on an aggressive crash-testing program at a nationally-recognized testing facility. "Even though no national crash standards existed, we needed some reassurance that our products would perform satisfactorily under crash conditions," explains Watkins. Convaid has been the industry leader in crash-testing its mobile positioning systems, using dummy weights up to 170 pounds. All Convaid products must meet a very high level of safety before being introduced to the market.

For children with special seating needs, early intervention is vital. In today's active, mobile world, positioning must be maintained in every product children use during every busy day. To meet this need, Convaid now offers three different mobile positioning systems available in more than 54 models and six designer colors. These systems provide more than 20 positioning options and are able to meet most positioning needs.

Focus on the future

Convaid is celebrating its 20th anniversary with an ambitious plan of product development. A new system demonstrating that one product can have both tilt-in-space and folding convenience will be available soon, as will a new contour concept. Other innovative products—not just imitations of those that already exist—are now coming off the drawing boards and entering production.

Convaid's products are made to last. Over time, the low frequency of repairs resulted in the company extending warranties from two to five years. As the Convaid heads into the late 1990's and quality continues to improve, they are seriously considering offering a lifetime warranty.

The company has been and will always remain a family business—one that cares about its customers and their special needs. It's a financially healthy and independent company, able to pursue exciting new product ideas without the restrictions or pressures that come from outside control or financing. Strategically positioned, Convaid is committed to providing innovative solutions for the needs of exceptional children.

"Oh, so ha

Kids, kittens and contentment. Recently, Mackenzie and her little sister, Kelly, visited a barn with lots of animals. Of all the animals, they fell in love with the cat.

Their mom loves to take the girls to lots of different places. Convaid's mobile positioning system lets them go where they want to go. Easily, conveniently and with the peace of mind the chair provides proper support. Even took a trip back East on the train. The Convaid chair folds up and fits in trunks, on trains and airplanes.

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Circle #305

For extra value, Convaid introduces the NEW *Cruiser Ready* which includes:

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- Headwings
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- Hip abductor
- Padded shoulder straps
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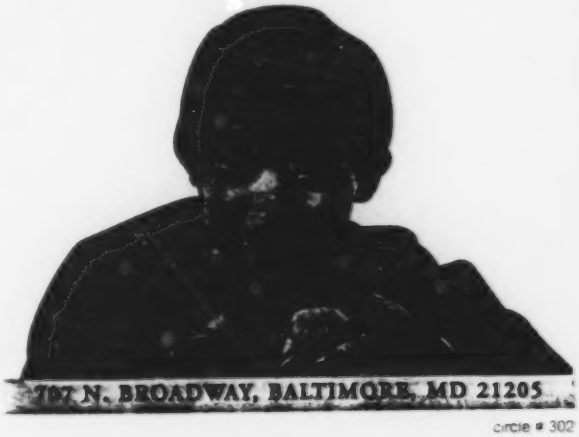
Founded in 1990, Barrier Free Lifts of Manassas, Virginia, produces affordable, high-quality lifts for homes and hospitals. While the company has introduced a full line of mobile floor lifts, its primary focus has always been ceiling-mounted lifts, such as the UniLift and UniLift Portable, which are truly the most "barrier-free." The UniLift Portable can be removed from its track system and carried to another room, another house or even to school, providing an inexpensive and utilitarian mobility solution; the original UniLift can be motorized, giving children who have adequate upper body mobility more independence. In addition, Barrier Free lifts offers a wide variety of sling designs, sizes and materials to provide an unlimited number of possibilities for meeting individual needs.

Barrier Free Lifts is dedicated to helping people achieve greater mobility. The company's goal is to provide a well-designed product that helps people help themselves. Their lifts are free of gadgets and clutter and are built for dependable and safe use. To find out more about Barrier Free Lifts, contact them by phone at (800) 582-8732, by e-mail at bflinc@erols.com, or on the World Wide Web at http://www.blvd.com/bfl.

circle # 301

Kennedy Krieger Institute

We at Kennedy Krieger Institute dedicate ourselves to helping children and individuals with disorders of the brain achieve their potential and participate as fully as possible in family, community and school life.



circle # 302

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Kennedy Krieger Institute

Many resources under one roof

For the child, adolescent or young adult with special needs, the Kennedy Krieger Institute (KKI) in Baltimore, Maryland has a multitude of resources—all under one roof. As an institution with a national focus, KKI can offer many more services and resources than most local facilities. KKI is home to more than 500 highly trained experts in a wide variety of fields, including rehabilitation and physical medicine, assistive technology, physical and occupational therapy, psychology and psychiatry, special education, developmental pediatrics, nutrition, orthopedics, orthotics, genetics, speech pathology, social work and nursing.

For almost 60 years, KKI has been a comprehensive resource for children with disabilities and their families from around the nation. KKI has the expertise to put all of the relevant information together in an easy-to-understand and coordinated assessment. Because of the breadth and integration of the services at KKI, staff members can make coordinated recommendations and implementation plans that can be transferred back to the child's or young adult's home and community.

For more information about how KKI can help you plan the future for your child and your family, write to Kennedy Krieger Institute, Central Referral Office, 707 North Broadway, Baltimore, MD 21205, or call (800) 873-3377.

525

Vail Products

An emphasis on safety and quality of life

Vail Products, in Toledo, Ohio, began in 1990 by marketing enclosed beds to hospitals and health care facilities. But as a small, family-owned business, Vail has always been concerned with the needs of families in their own homes, and it didn't take very long before it became apparent that there was a real need for an enclosed bed for home care. Vail refocused its design efforts, and, in 1992, came out with their flagship product, the Vail 2000 Enclosed Bed. Since then, hundreds of children and families have benefited from the distinctive Vail design and personal attention.

The Vail 2000's soft, padded enclosure reduces falls and injuries, controls night-time wandering while helping users fall asleep, and provides easy access for medical equipment such as IV lines.

The Vail 2000 is a specialty bed for both children and adults that completely encloses patients while in bed and provides a safe, protective environment. It offers the feel and fun of a canopy- or tent-style bed, allows the freedom to play and move about easily and creates a sense of security for calmer, less stressful sleep. Parents love the Vail 2000 because it allows their children to live in the comfort of their own home, without sacrificing the quality of their care. The Vail 2000's soft, padded enclosure reduces falls and injuries, controls night-time wandering while helping users fall asleep, and provides easy access for medical equipment such as IV lines. It comes with a removable bedskirt and border in any of six colors—no matter what the room's decor, the Vail 2000 will match perfectly. The bed is made of Staph-Check, a fabric manufactured exclusively for Vail Products that makes the bed bacteria-resistant, fire-resistant, fluid-proof, stain-resistant, odor-resistant, non-allergenic and anti-static.

Vail Products' main emphasis is safety for the child and quality of life for the entire family. They don't sell their beds through distributors or durable medical supply companies; the company sells direct to the customer, so they can work with each family on an individual basis to better accommodate the needs of each child. Vail beds are frequently covered by private and state-funded insurance; their staff will even help families put together insurance claims. All Vail beds come with a one-year warranty against manufacturing defects, and the company provides complete technical support by telephone for as long as the customer owns the bed. For more information, write to Vail Products, 235 First St., Toledo, OH 43605, or call (800) 235-8245.

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Now your child or loved one can enjoy the fun of a canopy or tent-style bed, plus the protection of a soft, sturdy enclosure that:

- Reduces falls and injuries.
- Controls wandering.
- Encourages more relaxed sleep.
- Accommodates medical equipment.
- Fits all ages from child to adult.
- Includes a removable bedskirt and border in your choice of colors.

A patented design, Vail beds are frequently covered by private and state-funded insurance. And they come complete with mattress, enclosure, manually adjustable head and foot, 1-year warranty, lifetime service, and easy step-by-step assembly video.

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Department of Pediatrics

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Putting the pieces together with compassion and dignity

At the Department of Pediatrics at Hackensack University Medical Center (HUMC), "user-friendly" is not just a catchy slogan. Beginning with the design of the buildings and the parking facilities, to the waiting areas and doctors' offices, and, most importantly, to the health care services provided, every part of the HUMC has been created to enhance the well-being of children and families. For example, parents can park directly underneath the Don Imus–WFAN Pediatric Center for Tomorrow's Children, which houses all ambulatory (outpatient) pediatric programs.

Coordination and interaction. All too often, parents and children receive their health care services in a facility that requires them to find their way from one clinical department to another—even from one building to another. In some cases, various clinical services are separated by more than physical distance; sometimes different professionals serving the same child do not seem to communicate with one another. The quality of pediatric care suffers as a result—and the family suffers, too.

HUMC knows that each child is a whole person, not just separate pieces. From the beginning, the focus is on coordination and interaction. In one division of the Department of Pediatrics, the Toys "R" Us Institute for Child Development, a developmental pediatrician works with each family and can schedule all referrals to appropriate specialists. But the pediatrician's involvement doesn't end there; the doctor coordinates care, working with parents to come up with a flexible, realistic approach to meeting the specific needs of the whole child and the family. Both the ambulatory (outpatient) and inpatient pediatric programs have been recognized for their quality-oriented services as well as their utilization of state-of-the-art medical technology.

Compassion and technical skills. HUMC has assembled a dedicated, highly-skilled, multidisciplinary medical and surgical team that is prepared to address the prevention, early diagnosis and compassionate, flexible management of the wide range of health care concerns encountered during infancy, childhood and adolescence. Depending on the unique needs of a specific child, a comprehensive pediatric health care team might include a developmental pediatrician, specialists in other pediatric medical specialties (hematology, oncology, critical care, neurology, neonatology, pulmonology, infectious diseases, rheumatology, cardiology, gastroenterology, radiology, oncology and others) and professionals in related disciplines like nursing, child life therapy, social work, audiology, speech and language pathology, occupational therapy, physical therapy, psychology, neuropsychology, special education and early childhood. The pediatric surgical services include all surgical subspecialties. All of these experts are dedicated to enhancing each child's life with compassionate care that respects the dignity of each child and family.

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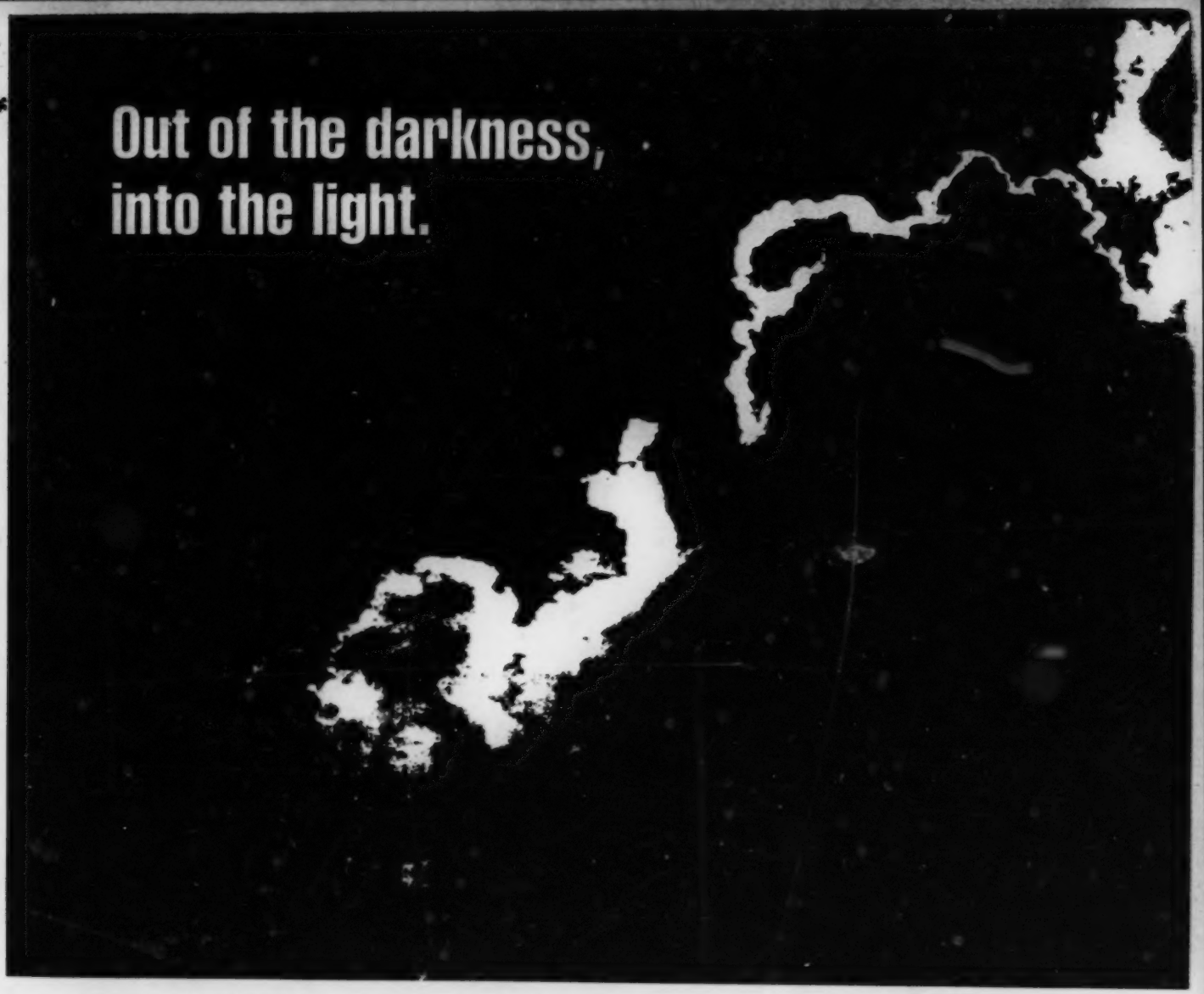

The National Organization for Rare Disorders (NORD) and *Exceptional Parent Magazine* will be *"Stepping Out in Dallas"* to bring you a conference you will not want to miss.

FOR WHOM: People and families of those affected by rare disorders and Professionals (social workers, nurses, educators)

WHEN: September 27 through 29, 1996

WHERE: Marriott Quorum
14901 Dallas Parkway
Dallas, Texas 75240
(214) 661-2800

FEES: Registration Fees: **NORD Member $85.00**
Non-Member $110.00
Each Additional Family Member $70.00

The Marriott Quorum is offering a special room rate of $89.00 per night single/double occupancy for NORD conference attendees.

Dallas is the place to be when NORD and *Exceptional Parent Magazine* go "Stepping Out" together and join forces in arranging a truly exceptional Patient/Family Conference. You won't want to miss the chance to meet with other individuals and families coping with rare disorders. Workshops and speakers will address issues and concerns that are important to those in the rare disease community. • Living with a Rare Disorder • How to Access Resources • Making the Most of Networking • Patients' Rights and Responsibilities • Support Systems • and much more! Interactive discussions are also planned with experts in metabolic diseases, assistive technology, genetic research, insurance reimbursement and the psychology of living with chronic disorders. There will be many opportunities to meet others coping with rare disorders!

If you are interested in receiving additional information on the conference and registration, kindly fill out the coupon below and mail to the address indicated before August 31, 1996. You may also contact NORD at 1-800-999-6673 and speak with either Jean Campbell (ext. 210) or Joseph Gatto (ext. 211). Space at the conference will be limited, so call now to guarantee a reservation.

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Address: _____

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Telephone: _____ **NORD Member:** ☐ **Yes** ☐ **No**

☐ Please send information on the 1996 NORD Patient/Family Conference.
☐ Please send information on NORD's programs and services.

Place in an envelope and mail to:
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P.O. Box 8923, New Fairfield, CT 06812-8923

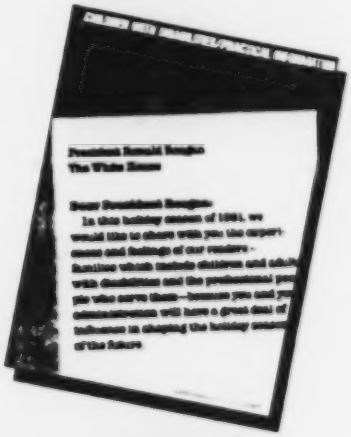
Requests for conference information should be received no later than August 31, 1996.

Circle #111

Dear Mr. President:

We are writing to request your assistance in assuring the continued support for P.L. 94-142 the Education for All Handicapped Children Act... [During the 1980 campaign], EXCEPTIONAL PARENT magazine requested statements from candidates... You responded by pointing out that the implementation of P.L. 04-142 was perhaps the greatest stride made to date... for the education of handicapped children... We hope you will reaffirm your pledge by endorsing current levels of federal funding for P.L. 94-142 and its support programs, and opposing any substantive changes in the statute.

—Letter signed by 285 members of the House of Representatives April 1982



DECEMBER 1981

"...No matter how hard it was to stay afloat in this ocean of troubles," writes Samantha Abeel of her disability, "there was something inside of me, something that became my life preserver—and that was writing."

"L.D. does not mean 'lazy and dumb.' It just means you have another way of looking at the world," says **Samantha Abeel**, 18, who was diagnosed in the eighth grade with dyscalculia, a learning disability that affects her understanding of numerical concepts. But Samantha did not allow her disability to prevent her from fulfilling her dreams. Instead, she began to nurture her talent and love for writing. The result was *Reach for the Moon*, a collection of poems and stories that won the 1995 Distinguished Book Award.

Now a senior at Traverse City Senior High School in Traverse City, Michigan, Samantha enjoys history, literature, art, music and theater. Samantha says that the success of *Reach for the Moon* has helped "heal the wounds from my learning disability. Now I realize how important it is to find an outlet and something you're good at." Samantha will attend Mount Holyoke College this fall.

Last fall, the Bedford Gallery in Walnut Creek, California, featured "Animal Portraits," an exhibit of 16 Chinese brush paintings by **Raymond Hu** of Alamo, California. Raymond, 19, who has Down syndrome, has studied this difficult art for six years under master artist Lam-Po Leong. In Chinese brush painting, the artist must work quickly and precisely to prevent the watercolors from spreading on the highly absorbent rice paper.

Critics say Raymond's animal subjects have an expressively human quality. Carrie Lederer, Bedford Gallery's curator, explains, "Each one has a soulful gaze, as if Raymond intrinsically knows the animals he sees." Raymond's award-winning works have been exhibited across the United States.

Raymond hopes his work will have a positive effect on others. "My paintings symbolize compassion for both humans and animals," Raymond explains. "We need to protect the environment, recycle more and not pollute."

A senior at San Ramon Valley High School, Raymond plans to attend college and continue to study art.

Tyra's Bree, by Raymond Hu. Watercolor and ink on rice-paper, 1995.

At first, Raymond's problems with fine motor skills made Chinese brush painting very difficult. His parents had to persuade him to keep going to his lessons.

In a speech at the 1995 Autism Society of America National Conference, 12-year-old **Mae Francois** eloquently described her life with autism and urged listeners to raise their expectations for children with the condition. "One of the most common misconceptions... is that most autistic people cannot learn as fast as other children," Mae told the audience. The speech received a standing ovation.

Mae, now 13, attends her local school and has been inducted into the National Junior Honor Society. "Mae has blossomed into an outgoing, self-assured young woman," says her mother, Phyliss. "She has won over the teachers who doubted whether a child with autism could be successfully included."

Because she has trouble writing quickly, Mae uses a laptop computer to take notes and do homework. At home in Lake Grove, New York, she enjoys exploring the Internet and communicating via e-mail with other children who have disabilities. Mae plans to attend college and become a scientific librarian.

In June 1993, Mae Francois, then 10 years old, received the Presidential Academic Achievement Award.

Dressed up for the school Halloween dance, Dan is shown at age 13 with sisters Debbie, 18 (left), and Kathy, 19 (right). Because of the rapid growth associated with Sotos syndrome, Dan has always been big for his age. Now his peers are starting to catch up, and Dan, at 6-foot-3 and 220 pounds, is ready to stop growing. "I'm big enough," he says.

When **Daniel Rogers** was born with Sotos syndrome, a condition that causes rapid physical growth and developmental delays, his parents were told he would probably never walk or talk. For the last 16 years, Dan has been proving his doctors wrong.

Dan, now 16, is an honor roll student who hopes to become a lawyer. In junior high, Dan was on the wrestling team for two years, winning the team's Courage and Commitment Award before being forced to give up the sport due to a congenital heart defect. A music lover, he was proud to make the cut for the school's top choir. Dan also enjoys the stage. He recently played Cinderella's father in a high school production of "Into the Woods."

Described by his mother, Gwyn, as "a busy, happy young man with more challenges than some, but with a positive attitude that is contagious," Dan works hard and never gives up.

According to 19-year-old **Betsy Smith** of Montclair, New Jersey, "It seems like the most natural thing in the world that I should be going to high school with all of the other teenagers in my town." Betsy made this remark as part of her testimony at a U.S. Department of Education hearing on states' compliance with the Individuals with Disabilities Education Act (IDEA).

At Montclair's High School of Visual and Performing Arts, Betsy, who has Down syndrome, explores her love of dance and theater in an inclusive setting. She sings and dances in many performances—even choreographing some of her own segments. Her mom, Joan, writes, "Keeping track of rehearsal schedules, cleaning the prop room and 'striking' the set have given Betsy real-life experiences in a setting she loves."

Betsy works as a teacher's aide for her former kindergarten teacher and also holds down a part-time job at an art museum. She is learning to take public transportation and manage her own finances.

Betsy met her best friend, Ebony Tucker, through their high school's performing arts program. Ebony (left) and Betsy (center) are shown with David Mank of the University of Oregon. The two girls spoke about their friendship at the March 1996 Association for Persons in Supported Employment Conference.

At age two, **Eli Abarbanel-Wolff** of Portland, Maine, suffered a stroke during surgery to close a hole in his heart. The result was hemiplegia, or limited mobility, on one side of his body. Eli began playing soccer at age four and played on junior varsity and varsity teams while attending Milton Academy, a prep school in Massachusetts.

Now a freshman at Brown University in Rhode Island, Eli trains with the varsity soccer squad and was a member of the team that represented the United States at the Pan-American Games in Argentina. This summer, he will compete as part of the U.S. soccer squad at the Paralympics in Atlanta.

But Eli's interests extend beyond athletics to public service. This year, Eli created the Disability Awareness Project, a program to connect Brown students with the local disability community. "People need to understand that all kinds of people can work together and be friends. Community involvement needs to be integral to people's lives," says Eli.

This fall, Eli Abarbanel-Wolff, 19, will enter his sophomore year at Brown University.

Megan Leaf, 15, has distributed more than 1,000 "love boxes," like this one, to young patients at Johns Hopkins Hospital in Baltimore.

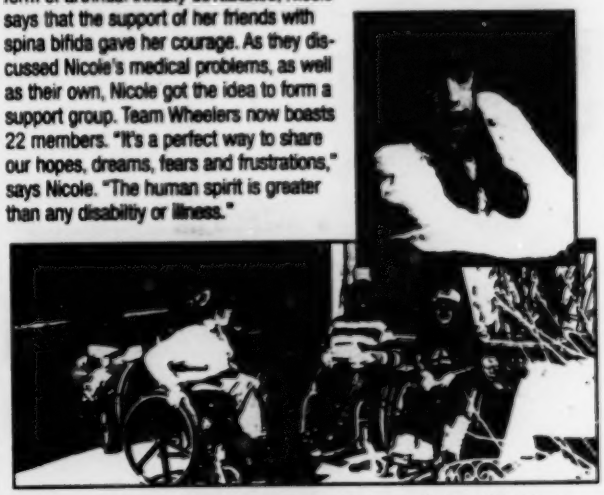
Megan Leaf, 15, of Forest Hill, Maryland, has neurofibromatosis, a condition that has led to blindness in one eye, balance problems, a growth hormone deficiency and learning disabilities. But Megan has never been one to dwell on her own problems; instead, she says, she lives by the creed, "Do something for others."

That creed has led Megan to start a large-print library for children with visual impairments at a local elementary school and to distribute more than 1,000 "love boxes" to, young patients at Johns Hopkins Hospital in Baltimore. Each love box consists of a coloring book, crayons, a stuffed animal, another small toy and a game. To cover expenses, Megan, who has spent much time in hospitals herself, solicits donations from civic groups, corporations and friends.

Megan's plans include college, a career in public relations and, of course, continuing to "do for others." "Volunteer," she urges others. "The smallest thing can make a difference."

Nicole Hymel, 16, of Kenner, Louisiana, has spent much of her life in and out of hospitals. At 13, Nicole, who has spina bifida, began volunteering at a local children's hospital to help others in similar circumstances. "It was rewarding to spend time with children and their families, knowing the struggles they were going through," she says.

But Nicole recognized her own need for support as well, especially when she was recently diagnosed with yet another disability—fibromyalgia, a form of arthritis. Initially devastated, Nicole says that the support of her friends with spina bifida gave her courage. As they discussed Nicole's medical problems, as well as their own, Nicole got the idea to form a support group. Team Wheelers now boasts 22 members. "It's a perfect way to share our hopes, dreams, fears and frustrations," says Nicole. "The human spirit is greater than any disability or illness."



Nicole Hymel, 16, (front) meets with members of Team Wheelers, the spina bifida support group she founded.

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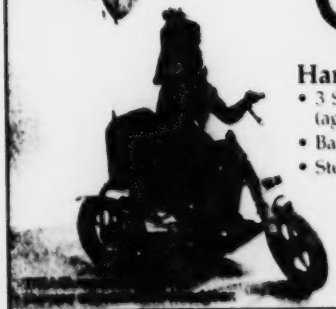

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Kevin Workman, 17, is a talented artist as well as the spokesperson for minority bone marrow drives in his hometown of Cleveland, Ohio. Kevin, who has chronic myelogeneous leukemia, hopes to find a bone marrow match for himself and raise awareness of the need for minority donors.

Kevin, who began drawing with crayons and markers as a second grader, now uses paint and canvas to depict the black Western experience. His talent has earned him invitations to the Cowboy Artists of America Camp in Montana the past two summers; both years, he was the youngest attendee. Kevin has also designed a holiday card that will be used by his local chapter of the Leukemia Society of America.

Says Kevin, "Painting is more or less my life. It's gotten me through some hard times—sometimes it's the only way I have to express myself."

(Above) Kevin Workman, 17, and (below) the holiday card he designed for his local chapter of the Leukemia Society of America.

At the age of 18 months, Marissa Anne Cohen, 12, of Pleasanton, California, was diagnosed with a severe to profound hearing loss. But that has never stopped her from doing what she wants to do. Now a seventh grader at the California School for the Deaf in Fremont, Marissa has been dancing since age three. She studies ballet, tap, jazz and hip hop.

Marissa relies on visual cues to begin dancing, but her precise internal timing carries her through her performances, often more accurately than her hearing classmates. Marissa, who aims for a career in television or in the movies, was one of three children chosen to appear in a 1993 AT&T commercial.

In August, Marissa will celebrate her bat mitzvah. Marissa will use American Sign Language (ASL) to sign a selection of prayers and the blessings for the Torah. She will also use ASL to explain the Torah portion read by the rabbi.

Marissa Anne Cohen, 12, of Pleasanton, California, has a smile as bright as the lights she'll see at her dance recital.

Catherine Armstrong, 15, of Alexandria, Virginia, was born blind. But what she can't see with her eyes she makes up for with her imagination. As a member of her high school debate team, she participated in the storytelling event, which involved telling original stories as well as those written by others. Her coursework also includes biology, pre-calculus and history. She is fluent in Spanish, plays the trumpet and was recently chosen to participate in the all-state band.

Catherine Armstrong, 15, practices trumpet in her backyard.

Catherine's hobby is HAM radio, which she describes as "a radio version of the Internet." To become a HAM radio operator, she needed to get a license, which meant studying electronic theory and learning Morse code. Through HAM radio, Catherine has talked to people from as far away as the Czech Republic and Sweden.

Catherine recommends that parents give children with disabilities the freedom to pursue their goals. "Don't stifle their dreams," she says.

In 1994, **Jessica Vohs,** of Brookline, Massachusetts, combined her love of art with a desire to serve the community by joining City Year, Boston's public service youth corps. Jessica, who has cerebral palsy, uses a wheelchair and is non-verbal, was assigned to a City Year team at the Horace Mann School, a public school for deaf children housed in a Boston elementary school. Using her communication notebook, a device that allows her to communicate by pointing to symbols and pictures, and some sign language, Jessica worked as a teacher's aide in an art class.

Jessica, now 25, lives in her own apartment and works as a teacher's aide in the art department of another Boston public school. She designs projects for her classes, as well as sets and costumes for theatrical performances. Jessica's plans include attending art school, starting her own business and marrying her boyfriend, Cody.

To young people with disabilities, Jessica Vohs wants to say, "I think we all have a gift to bring to the world. Find that gift and share it with as many people as you can. Do not limit yourself or allow yourself to be limited by anyone." Here, Jessica shares a hug with her boyfriend, Cody.

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Although progressively losing her vision and hearing, **Jenny Lea Graham,** 18, of Southlake, Texas, has not given up her dreams. Born with Rubella syndrome, a condition caused by her mother's exposure to German measles during pregnancy, Jenny is working hard to finish as much of her education as possible before becoming completely blind and deaf.

As a high school sophomore, Jenny elected to complete her junior year simultaneously through a correspondence course. After graduating this June, she'll immediately begin a college preparatory program. In September, Jenny will attend Southwest Texas Junior College, where she plans to major in English. She hopes to become an English teacher, specializing in teaching students with special needs.

Jenny serves as an assistant coach for her school's Special Olympics team and as a tutor in the special education department. Very involved in her church's youth group and outreach program, she also volunteers in the church nursery.

While in San Antonio for an assistive technology assessment, Jenny, then 17, visited the Alamo.

Jon Doxey, 17, of Avondale Estates, Georgia, has specific learning disabilities in the areas of math and language. When first diagnosed with a speech/language disorder at age three, doctors told his parents he would probably never learn to read. Because he did not learn in the same way as most children, his parents decided to homeschool him. Jon now reads at a college level.

For the past three years, Jon has worked for *The VOX*, a teen newspaper distributed to schools in three counties. The paper provides a forum for students to express themselves by writing about their lives through non-fiction articles, short stories and poetry. Jon writes occasional articles, but spends most of his time doing design and layout.

This fall, Jon will enter college. Inspired by an archeology course he recently took, Jon is considering a major in anthropology or geology.

Jon Doxey, 17, a staff member of *The Vox* teen newspaper in Atlanta, uses Quark Express, a computerized design program, to create the paper's layout and design.

Cheers! Jason Kingsley, 21, enjoys some of the benefits of adulthood—like a nice cold beer in the shade. Jason's dreams for the future include getting a job, living in his own place, getting married and maybe even being a father.

As a young boy, **Jason Kingsley,** who has Down syndrome, made several appearances on *Sesame Street, All My Children* and other television programs. In 1994, Jason and his friend, Mitchell Levitz, published their book *Count Us In: Growing Up With Down Syndrome*. The book, published by Harcourt Brace & Company, is currently in its fourth printing.

Jason, 21, who lives in Chappaqua, New York, and graduated from Lakeland High School with a full academic diploma in June 1994, now attends the Maplebrook School in Amenia, New York, a post-secondary program for students with learning disabilities. He is the school's first student with Down syndrome. This year, he was voted dorm representative.

In addition to his studies, Jason holds down a part-time job at a local Head Start office. Next year, he will participate in Maplebrook's Apartment Living Program. "I want to live on my own some day like Mitchell," Jason explains. "He is a good inspiration for me."

Of her wheelchair, 17-year-old **Melissa Mitchell** of Tacoma, Washington, says, "I don't think being in one of these things should stop anybody from leading a normal life." Melissa, who has cerebral palsy, also has an independent spirit and a positive attitude that pervades everything she does. She designs her own Individualized Education Plan (IEP) and physical therapy regimen. At school, she is an honor roll student, a member of the National Honor Society and on the staff of the school newspaper and yearbook. After school and during the summer, Melissa works with children at the Lakewood YMCA.

Melissa, who hopes to become a lawyer or journalist, urges other children and young adults with disabilities to advocate for themselves. "It's going to be hard," she says, "but if you can reach the point where one person treats you like a normal person, it's worth it."

"The word 'can't' has great power in diminishing someone's ability," says Melissa Mitchell, 17, who does not allow her cerebral palsy or wheelchair to keep her from pursuing her dreams.

Berkshire Meadows

Nestled in the serene beauty of western Massachusetts' Berkshire Hills, Berkshire Meadows' carefully designed fifteen-acre campus offers a comprehensive, integrated year-round residential program for children and adolescents who are severely developmentally delayed and may be multiply disabled.

Like other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.

The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

Weekends and holidays are for fun. We take full advantage of the loveliness of our natural surroundings, and of the receptive friendliness and extensive activities of local communities.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

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Circle #91

In 1989, **Adam Thal,** of Washington, D.C., joined a local Boy Scout troop. Although Adam, who has mild to moderate retardation, was the only troop member with a disability, other Scouts were accepting and supportive. In June, Adam, now 22, will earn the highest Scouting rank possible—Eagle Scout.

Eagle Scout requirements include completing a personal project. Influenced by the shooting of former White House press secretary James Brady, a friend of his mother, Lorraine, Adam organized a gun turn-in program for his city. Supported by local authorities, the turn-in was held in November 1995 and received coverage on two local television networks and in a local paper.

Adam Thal, 22, hones his rope skills with fellow Boy Scouts.

After 15-month-old **Caya Consunji** was diagnosed with a profound hearing loss, her family emigrated from the Philippines to California in search of better educational opportunities for her.

Now 17, Caya, who lives in Redwood City, communicates through speech and lip-reading. She received a full academic scholarship to the Menlo School, a college-prep school where she was an honor student and varsity athlete. She has won numerous awards, including a silver medal in the National Latin exam, the 1995 Chrysler Junior Golf Scholarship and the 1993 Ninoy Aquino Memorial Award for Youth Achievement, the highest community service award given to Filipino-Americans. This fall, Caya will attend the University of California at Berkeley.

Caya Consunji, 17, and her mother, Christine, enjoy a sunny California day.

In 1994, Caya spoke at the Fourth Asia Pacific Congress on Deafness. "I am the result of a group effort," she told the audience. "My family, friends, coaches and teachers inspire me to work hard and believe in myself."

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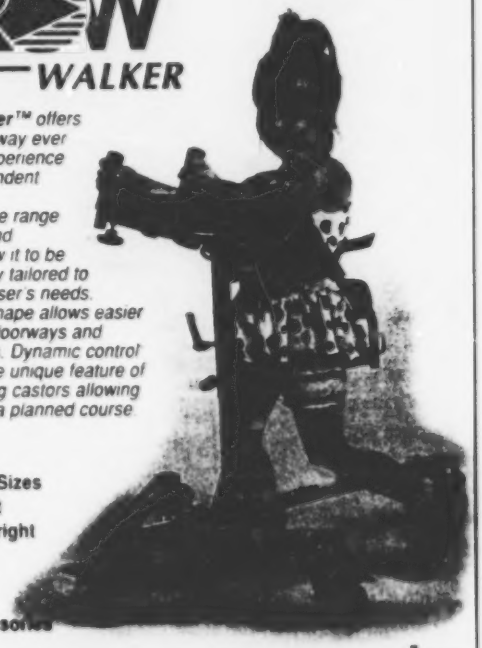

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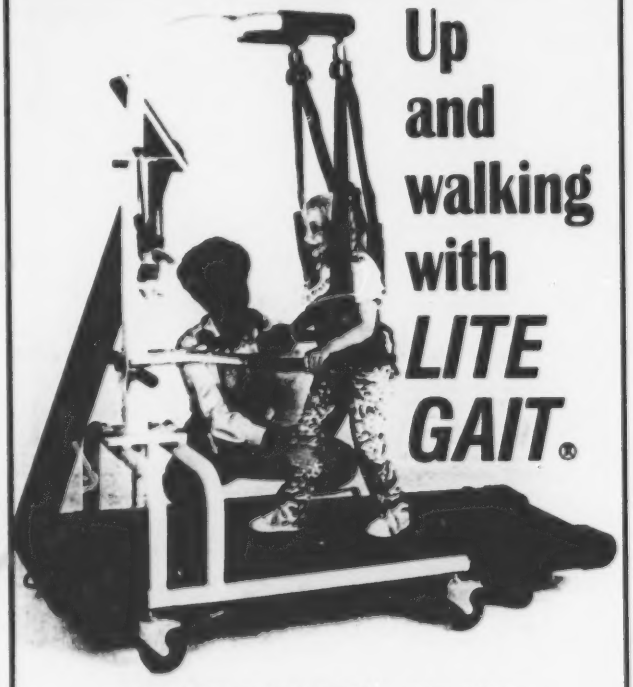

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Circle #52

Christine Bales, 19, of Castleton, Vermont, is working to break down misconceptions about people with disabilities, especially among law enforcement personnel. Christine, who has cerebral palsy and a visual impairment, was first invited to speak to police cadets in 1994 after writing a letter to instructors at the Vermont State Police Academy. Now, twice a year, she discusses disabilities with the academy's cadets. Says Christine, "People with disabilities are like everybody else. The difference may be that they are in a chair, or they may be blind or deaf. Actually, everyone has disabilities; some disabilities just show a little more than others."

Christine has competed in Special Olympics events for the past 10 years. She plays basketball, swims and participates in track and field events. A high school graduate, Christine has taken some college classes and hopes to earn a degree in psychology.

Christine Bales, 19, (right), and her twin sister, Cassie, are all smiles at a recent Special Olympics event. Christine competes in track and field, swimming and basketball.

Although she may not remember her mother's successful fight to change Medicaid regulations for children, like herself, who needed home health care services (see "The Long Road Home," page 68), **Katie Beckett,** 18, of Cedar Rapids, Iowa, has become a health care advocate in her own right. Having testified before Hillary Rodham Clinton and made several presentations at conferences, Katie says, "I will continue speaking out on issues concerning people with disabilities, such as universal health care. As long as I'm needed, I'll keep talking."

Katie, who has a tracheostomy and uses a respirator, completed an internship at EXCEPTIONAL PARENT and wrote for her high school newspaper. This fall, she will attend Drake University's School of Journalism and Mass Communications in Des Moines, Iowa. Katie's career goal is to join the editorial staff of an entertainment magazine.

"Having a disability makes a person appreciate life's little things more," writes Katie. "A disabled person doesn't take their health or day-to-day activities for granted."

Laura Mayhall, 18, of Salem Oregon, was born profoundly deaf. Now a senior at the Oregon School for the Deaf (OSD), Laura has been awarded a Merit Scholarship and will attend the Rochester Institute of Technology/National Technical Institute for the Deaf in the fall. Laura plans to study photography and computers.

Laura serves as treasurer for her school's student government, plays varsity volleyball and basketball, and is the programmer for OSD's award-winning World Wide Web site on the Internet. She is working on the school yearbook and is a member of a drama troupe called "Hope Is Vital," which performs interactive presentations to raise awareness of and seek solutions to issues faced by teenagers today.

Laura is also an active member of her church and has presented three "sermonettes" in sign language for her congregation. She has also participated in Habitat for Humanity, a Christian ministry that builds housing for low-income families.

Joseph Nartker (left) is an enthusiastic member of his Cub Scout pack.

Joseph Nartker, 11, of Beavercreek, Ohio, plays little league soccer, baseball and softball. Last year, he had a part in a play presented at a local university. He also has Down syndrome.

Now a fourth grader, Joseph attends Catholic school, where he has been included in regular classes since kindergarten. Joseph recently made his First Communion, and next year, he plans to become an altar boy.

Recently, Joseph participated in a program called "Everybody Counts," where he and four of his classmates without disabilities spoke to students at another school about living with Down syndrome. According to his mother, Catherine, Joseph "lives life to the fullest and finds beauty everywhere. His attitude is always, 'Yes I can!'"

Laura Mayhall (left) performs in a "Hope Is Vital" performance.

Alexis Brown, 12, who has cerebral palsy and lupus, knows that being in the hospital can be a lonely and scary experience. During a long hospitalization three years ago, Alexis, who lives in Harwich, Massachusetts, came up with the idea for *Bearable Times*, a quarterly newsletter by and for children in hospitals. "It wasn't much fun in the hospital," Alexis explains, "because I couldn't always visit with the other kids or play games. So it was great to get mail." A newsletter, thought Alexis, would give children in similar situations the chance to "share feelings and ideas."

Alexis Brown, enjoying a day at the beach, makes no secret of her favorite color. Her newsletter, *Bearable Times*, is also printed on purple paper.

Alexis, who has been using computers since the age of five, often meets potential newsletter contributors while cruising the Internet. She also uses her computer to produce the 24-page newsletter, which is distributed through hospitals nationwide. Each issue features stories, poems, riddles, word games, drawings and a pen-pal section. For more information on *Bearable Times*, visit Alexis' World Wide Web site on the Internet at http://www.harwich.edu./bear/index.html.

"Being on *Mister Rogers' Neighborhood* was one of the greatest experiences in my life," says **Jeff Erlanger,** 25, of Madison, Wisconsin. "I'm honored by the fact that the episode is rebroadcast so often… I feel good knowing that I've helped people gain a better understanding of disabilities." (See page 78.)

At the Olin Sang Ruby Union Institute summer camp, where he worked in 1991, Jeff Erlanger shares a laugh with camper Ben Beraha.

Sixteen years after appearing on the show, Jeff, who has quadriplegia, is completing his undergraduate degree in political science at Edgewood College in Madison, Wisconsin. He hopes to have a career in journalism. Outside of class, Jeff enjoys following political commentary on television and the Internet; he is also an avid sports fan.

For the last five summers, Jeff has worked as a counselor at the Olin Sang Ruby Union Institute summer camp, run by the Union of American Hebrew Congregations. Jeff attended the camp as a child and is the camp's first counselor with a disability.

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Circle #87 539

Rosimar Hernández Ruiz takes a plunge in the ocean at Mar Sin Barreras, an accessible beach she designed herself.

Rosimar Hernández Ruiz, 17, of Carolina, Puerto Rico, has a dream—"to eliminate architectural barriers and the barriers of hearts around the world." At age 12, Rosimar, who has cerebral palsy with spastic quadriplegia, saw a need for an accessible public beach and designed *Mar Sin Barreras* (Sea Without Barriers), a beach featuring a walkway out to the ocean with protected pools, enabling people in wheelchairs to move themselves into the water.

She sent her plan to government officials, but no one responded. When a new governor was elected, she resubmitted her proposal directly to him and received a positive response. *Mar Sin Barreras* opened to the public in July 1995.

Now a high school junior and honor student, Rosimar plans to attend college and, eventually, become a physician with a specialty in psychiatry. "Keep fighting for your dreams," says Rosimar. "They might look far away, but everything is possible."

A U.S. Department of Transportation artist created this rendering of *Mar Sin Barreras.*

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Circle #70

The World of GM Mobility

The people at General Motors, and GM dealers nationwide, recognize the importance of mobility to everyone's life, especially to the millions of Americans who have some form of disability and need adaptive equipment on their vehicles. GM also recognizes the transportation challenges faced daily by parents of children with disabilities. Such considerations prompted GM and the Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac and GMC Divisions to launch the GM Mobility Program in early 1991.*

What is GM Mobility?

The GM Mobility Program provides comprehensive resource information, as well as after-market adaptive equipment reimbursements (up to a maximum of $1,000 per vehicle), to make it easier for individuals with disabilities to take full advantage of today's personal transportation market.

Free resource information

Central to the GM Mobility Program is a free resource packet, customized for each state, which lists mobility equipment installers and driver assessment centers, along with a list of wheelchair compatible GM vehicles.

"Determining a customer's modification needs is the first step in finding the right vehicle," says Mary Anne Meade, manager of the GM Mobility Program. "Assessment facilities can evaluate a person's requirements and recommend appropriate vehicle modifications."

The GM Mobility Assistance Center can also provide customers with a list of organizations offering services in transportation, including possible sources for funding mobility conversions. State rehabilitation services agencies, insurance companies and local community service organizations may offer financial assistance for conversions.

GM Mobility also offers a complimentary 20-minute GM-produced resource video, *On the Move Again*. This open-captioned videotape talks about what to do, where to go and who to see if your vehicle needs adaptive equipment. It also shows various types of vehicle modifications and adaptive equipment.

Up to $1,000 reimbursement

The GM Mobility Program reimburses up to $1,000 toward the cost of any after-market adaptive equipment for drivers or passengers when installed (or reinstalled) on any eligible purchased or leased new GM car, van or light-duty truck. Dealer demonstrators and special event units are also eligible for reimbursement. Adaptations may include equipment such as hand controls, wheelchair or scooter lifting devices, pedal extenders and grab bars or hand straps.

Always striving to benefit as many consumers as possible, GM Mobility recently expanded the program to include alerting devices for drivers who are deaf or hard of hearing. As soon as General Motors discovered that such new technology existed in the marketplace, they quickly took steps to add these devices under their "umbrella" of reimbursable items. Their *Alerting Device* brochure lists mail order companies that sell such devices; many of these companies also provide catalogs with other helpful devices for consumers with hearing impairments.

A caring company

General Motors and its car and truck divisions have helped more than 28,000 consumers and their families gain more independence by helping them acquire the mobility aids needed on their new GM vehicles.

"Our effort is focused on helping people with disabilities, and their families, to select and adapt their new GM vehicles to meet their specific transportation needs," says Meade. "GM wants to be part of their support team. We're here to help." **EP**

For information

For a free state information packet and details about the GM Mobility reimbursement program, contact:

GM Mobility Assistance Center
P.O. Box 9011
Detroit, MI 48202
(800) 323-9935 (Voice)
(800) 833-9935 (TTY)

Questions about the GM Mobility Program?

Visit a local General Motors dealer, or call a GM Customer Assistance Center:

	Voice	TTY
Chevrolet/Geo	(800) 22-1020, Prompt 3	(800) 833-CHEV
Pontiac	(800) 762-2737	(800) 833-PONT
Oldsmobile	(800) 442-6537	(800) 833-OLDS
Buick	(800) 521-7300	(800) 83-BUICK
Cadillac	(800) 458-8006	(800) 833-CMCC
GMC	(800) 462-8782	(800) GMC-8583

• Information about GM Mobility is also on the World Wide Web at http://www.gm.com/standard/crossrds.

** Note: The Saturn Corporation and GM of Canada also administer mobility programs. For information about the Saturn program, call (800) 553-6000, voice; (800) 833-6000, TTY; and for GM of Canada call (800) 463-7483, voice; (800) 263-3830, TTY. From the United States, call GM of Canada at (905) 644-3063.*

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

541

General Motors.

GM MOBILITY PROGRAM

"The GM Mobility Program can help you a lot. I know because my mom is part of it."

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An active honor roll student, Tammie Groth doesn't believe in obstacles. Neither does her mother, Connie, one of the many General Motors employees whose own lives are affected by physical disability. It's their valuable insights that help make the GM Mobility Program work. Transportation means independence. That's something the people at General Motors know from their own experience.

Call the GM Mobility Assistance Center. We'll give you: • The names of local companies that provide driver assessment services, adaptive driving devices and vehicle modifications. • An informative videotape, "On the Move Again." • Suggestions for the General Motors cars and trucks that might work best for you. Then, if you buy or lease a new GM vehicle, we'll reimburse you up to $1000 toward the cost of adapting it or reinstalling your own adaptive equipment. Call 1-800-323-9935 (TDD users: 1-800-TDD-9935), or contact your Chevrolet, Pontiac, Oldsmobile, Buick, Cadillac or GMC Truck dealer to find out more.

The Supreme Court... upheld a 1980 decision by a Texas Federal Appeals Court that Amber Tatro, a child with spina bifida, must be provided with clean intermittent catheterization by the school district so she can attend public school in the regular classroom. The court decided that this service was within the definition of related services under P.L. 94-142... Mrs. Tatro always took Amber to court hearings because she felt it was important for the judge to see Amber and "know" the person who was being talked about. At times, [Amber] poignantly would ask, "Did the judge say I could go to school?"

—"Related Services and the Supreme Court, A Family's Story," October/November 1984

OCTOBER/NOVEMBER 1984

The Golden Age of Special Education

by Edwin W. Martin

At the White House in 1979, President Jimmy Carter (left) and Ed Martin (right) share in the celebration of the establishment of the Department of Education. Martin was appointed Assistant Secretary for Education on the same day.

Edwin W. Martin, Ph.D., is generally recognized as the major architect of federal policies affecting children with disabilities during the critical period from 1965–1980 when most federal programs were put in place. In his speeches and writings, he expressed the philosophical foundations that underlie the Education for All Handicapped Children Act.

For this 25th Anniversary issue of EXCEPTIONAL PARENT, we asked him to tell us about his role in what has been called the "golden age of special education."

Q How did you get involved in federal policy? Was that your career ambition?

A No. In 1965, I was a college teacher training speech pathologists and audiologists when I received an offer to spend four months as an "expert" for the U.S. Office of Education reviewing proposals from colleges and universities seeking financial support for their speech pathology and audiology training programs.

That led to my being hired the next year by Representative Hugh L. Carey (D., N.Y.) as director of his new ad hoc Subcommittee on the Handicapped. Although it was difficult for my family and for the University of Alabama, where I had been teaching, for us to return to Washington, we all agreed that this was a chance for me to serve our country, as President Kennedy had said. So I went, seeing it also as a kind of post-doctoral fellowship in political science.

Q What made you decide not to return to the university?

A My wife, Peggy, tells a story that one night, when we were sitting over dinner, I told her that Congress had passed our bill that day and that it would help at least a million children. I don't even remember the incident, but she said that when she saw the gleam in my eyes, she immediately knew we could not return to the university as long as that kind of activity was possible—and she was right. I had been used to helping small numbers of children with disabilities and training professionals, both of which I loved and have continued to love. But the realization that I could use the same talents to bring about national change was astonishing.

Q What do you consider your major accomplishments?

A First, these are not solely my accomplishments but are the work of many people—parents, professionals, members of Congress, their professional staffs and fellow Executive Branch colleagues. In many ways, I had the good fortune to be in the right place at the right time, when the people of our country were willing to make changes.

One major accomplishment was the first Education of the Handicapped Act, passed in 1966. It's not well remembered, even by special education experts, but it set into motion the whole process that led to education for each child with a disability becoming national policy 12 years and three presidents later.

The hearings before the Carey Committee gave parents and educators a chance to tell their stories. We heard how children were turned away from schools. We heard federal and state officials tell us they had no idea how many children with disabilities there were. We heard them estimate that only one child out of five who needed a special education was receiving it.

In all, we compiled more than 1,000 pages of testimony and then introduced legislation that would have been a broad and comprehensive attack on the problem. It mandated help for school districts, books and materials, support for innovative and exemplary programs, research and teacher education, strengthening of state education agencies and more.

It was not possible to get that comprehensive bill through Congress in 1966, but we did see three major parts passed: 1) a program of grants to the states to help local school districts start or improve programs; 2) the creation of the Bureau of Education for the Handicapped, which would report directly to the U.S. Commissioner of Education; and 3) the creation of the National Advisory Committee on Handicapped Children. These programs received bipartisan support in the Congress and were signed into law by President Johnson.

Q Why do you mention bipartisan support?

A While then, as now, those types of programs were usually supported by the more liberal and moderate members and more likely to be opposed by conservatives, in those days, Congress was a much nicer place. Members tried to work with each other on all but those issues that evoked strong partisan differences. I never heard Congressman Carey make a speech, for example, when he did not give Republican members credit for supporting and sponsoring the legislation.

Q The public has come to have a low regard for bureaucracy. Was having a Bureau of Education for the Handicapped really important?

A It was more important than I can communicate in this brief interview. It could be a book in itself. First, it meant that for the first time, we would have direct access to the U.S. Commissioner of Education and that issues of educating children with disabilities would have to be on the table for policy and budget discussions. In the past, special education was a small part of some other huge program and was often overlooked.

Second, we gathered a staff of excellent professionals, most with direct special education experience, and parents.

continued on page 64

Ed Martin (left) receives a congratulatory handshake from President Lyndon B. Johnson upon the signing of the first Education for the Handicapped Act in 1966.

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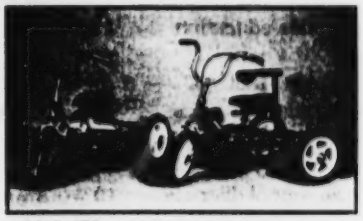

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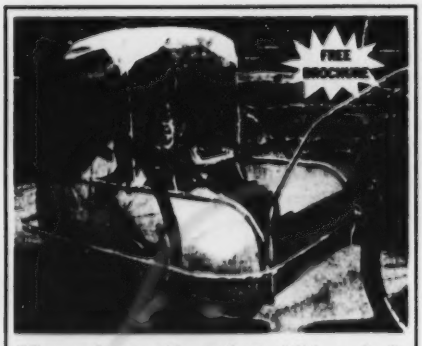

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Circle #20

continued from page 61

which allowed us both to work with Congress to pass many critical pieces of legislation and to give focus and leadership to the efforts of parents and professionals across the country. We helped bring together groups that had never worked together, although they had similar goals. For example, early childhood specialists and Head Start people met with special educators who were interested in starting infant and early childhood programs for children with disabilities. These collaborations helped us get the various administrations and the Congress to fund those efforts and to help establish local and state programs.

To return to an earlier question, my other major accomplishment is the obvious one—P.L. 94-142, the Education for all Handicapped Children Act, passed in 1975 to be fully effective in 1978. Together with the federal court decisions of the same period, that legislation ended the series of meetings I had in my lifetime with teary-eyed parents, terribly pained and frustrated because their children had just been rejected by their local school and they had nowhere else to turn and no legal rights to an educational program.

That bill, I feel, was the most significant education bill ever passed by Congress, even more important than the Higher Education Acts and the Elementary and Secondary School Acts, which have also had profound positive effects. P.L. 94-142 literally changed the fabric of our nation and tried to end centuries of discrimination.

Q You have said in the past that P.L. 94-142, now known as the IDEA (Individuals With Disabilities Education Act), was not entirely successful, though it achieved its broad goals. What remains to be done?

A Unfortunately, a great deal remains to be done. First and foremost, parents and educators must create a system for measuring the outcomes of special education. It must take into account not only academics but also such practical issues as

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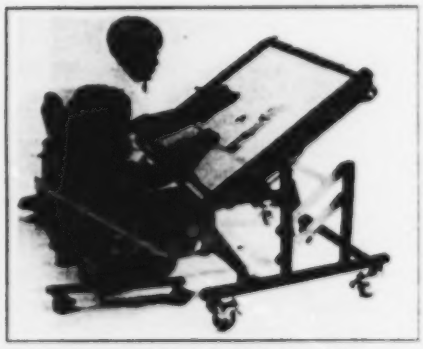

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self-image, independence, post-secondary school education or vocational training, employment and social relationships within the community. Schools must begin to measure and keep track of such things so they can tell parents what their track record is. That doesn't mean that every child will succeed, but it will give everybody the information they need to improve programs.

Second, we must pull together more effectively to fight the attacks on special education programs. Most threatening are those that sacrifice children for cuts in budget—attacks often hidden in block grant proposals. The whole history of state and federal legislation shows that children with disabilities need very specific, categorical legislation if they are not to be lost in the shuffle. There are countless examples of children with disabilities being overlooked and losing resources when combined into larger programs.

Unfortunately, some very well-meaning advocates for children do not realize that by proposing the end of special education programs in the name of "total inclusion," they will bring about a return to the "bad old days." I believe there can be effective inclusion programs for some children, perhaps for many children, but there must be special programs as well, and special education funds must be targeted not on improving *all* education but on *individualizing instruction* for children with real disabilities.

Research has demonstrated that specially designed programs work for children with disabilities. This type of programming should be expanded. Similar research should be done on "inclusive" programs so we can identify the effective ones. At present, there is no comprehensive research evidence that inclusion works. What we have is rhetoric, hopes and high aspirations, but no proof to offer parents. **EP**

In 1982, while serving as president and CEO of the National Center for Disability Services, Ed Martin enjoys a sailing excursion off Long Island Sound with a young friend, Jimmy.

Edwin W. Martin, Ph.D., worked for the House of Representatives when it passed the first version of P.L. 94-142 and later served as director of the U.S. Bureau of Education of the Handicapped under Presidents Johnson, Nixon, Ford and Carter. When the Department of Education was created, he became its first Assistant Secretary for Special Education and Rehabilitative Services.

After leaving government, Dr. Martin became president of the National Center for Disability Services, an internationally renowned education and rehabilitation program. He also taught public policy at the Harvard Graduate School of Education and at Teachers College, Columbia University. Since 1984, he has served as a member of EXCEPTIONAL PARENT*'s Editorial Advisory Board.*

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The Long Road Home

The creation of the "Katie Beckett Waiver"

by Julie Beckett

Julie Beckett (left) cuddles with 18-month-old Katie at St. Luke's Hospital. It was September 1979, and Katie had been in the hospital for more than a year.

When my daughter, Katie, was born in March 1978, she had relatively few medical problems, despite the fact that she was three months premature and weighed just over two pounds. In fact, she was able to come home in May—before her actual due date—and throughout the summer was a happy, healthy infant.

But on August 29, Katie suddenly became irritable and uncomfortable. A spinal tap the next day revealed the possibility of either meningitis or encephalitis. We were sent home from the pediatrician's office with instructions to return the next day.

By early that morning, Katie seemed less irritable, but our doctor, not wanting to take any chances, put her in the hospital for observation. That afternoon she took her first bottle in three days. Early the next day, I called and was told she was doing well. But no sooner had I left the house, than the hospital called back to say that Katie had had a grand mal seizure and was being taken to the intensive care unit in severe respiratory distress. Five hours later, another grand mal seizure sent her into a coma and placed her on life support. The doctors believed the encephalitis had attacked the nerve center in her brain and caused her to begin quick breathing.

On Labor Day, Katie lay practically lifeless in the NICU. The doctors ran tests to see if she had any brain activity. I remember them saying that the results would show us "if decisions would have to be made." When the tests were completed, the neurologists explained that there was activity in all parts of Katie's brain, but that they could not predict when she would wake up. And so we waited. Three weeks later, Katie opened her eyes but was totally paralyzed, unable to move her arms or her legs. Our long journey had begun.

Over the next few months, Katie had her ups and downs; she began to move her legs, but she couldn't breathe or swallow. A tracheostomy tube was placed in her throat and a gastrostomy tube in her stomach. Although she looked sick, she was still a happy baby and gave much hope to parents whose infants were in the same unit. Because she was making few strides toward breathing on her own, the doctors decided to try inserting pacemakers in the nerves that controlled respiration.

The surgery was done at a hospital in Chicago where the atmosphere and attitude were different from what Katie's father and I were used to. It taught us to be outspoken, to seek out allies and to use the knowledge we possessed from our months of interaction with health professionals. Unfortunately, some of Katie's nerves had already atrophied, and the surgery was pronounced a failure.

Katie (left), now 18, poses for a mother-daughter picture with Julie.

Where's Katie now? *For an update to Katie's story, see page 57.*

Catch-22

Six months later, Katie started to breathe on her own, and her doctors approached us about taking her home. She was now on the ventilator only 16 to 18 hours a day, and, because her swallowing reflex had improved, she had started handling her own secretions. Discharge planning began shortly after her third birthday.

At that point we were notified that Katie's medical bills had reached the $1 million limit of her Blue Cross/Blue Shield major medical policy. She had become eligible for SSI in 1979, and I had applied so we would have Medicaid to assist with health insurance co-payments and deductibles. (In Iowa, Medicaid eligibility is automatically granted with enrollment in the SSI program.) Since Katie's Blue Cross/Blue Shield coverage had been exhausted, her bills would be covered by Medicaid, but there was a catch: Medicaid did not pay for home health care, and we wanted to take Katie home.

We consulted with Social Security and then with the state Medicaid

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Photos courtesy of J. Robert Russell Photography

With new Medicaid legislation passed in 1981 that allowed her to receive care at home, three-year-old Katie (center) packs her things and prepares to leave the hospital with the help of her parents, Julie (left) and Mark (right).

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director. Both explained that "rules were rules." We were told we could apply for an exception to the policy, although the state had never before granted an exception to anyone. We were determined to be the first.

In June 1981, I approached my congressman, Tom Tauke. In his office, I met with his aide, Hazel Wharf. A strong advocate for the elderly, she understood what I was up against. She suggested that a visit by the Congressman to Katie's hospital bed would help him understand the situation more clearly.

When Congressman Tauke visited the hospital, he listened closely to what we had to say and learned through seeing that this child really did deserve to be home. He was also swayed by the cost-of-care data we presented. We explained that Medicaid was paying between $15,000 and $18,000 a month to keep Katie in the hospital; at home, that amount would be reduced to between $2,500 and $3,000.

Data in hand, he personally walked the exception through the Department of Health and Human Services in Washington. Several months later, his office received the answer—our application for an exception to the rules had been rejected! The department wrote that "Medicaid regulations [did] not allow [them] to pay for home care."

President Reagan to the rescue

The next day, Congressman Tauke hand-delivered a letter outlining Katie's case to then-Vice President George Bush, with whom he was sharing a plane ride to Iowa. Mr. Bush called the congressman back to his private quarters on the aircraft, and they talked for most of that day—not just about Katie, but about all the children the congressman had learned about in his visit to Katie's hospital.

One day later, the Vice President entered the Oval Office and, throwing the letter onto the desk, told President Reagan something needed to be done about this problem. The President picked up the phone, called Health Care Financing Administrator Carolyn Davis and told her to "find this little girl and fix the problem."

Dr. Davis was well informed about this issue; throughout her career she had seen many children living in hospitals. She informed the President that if they made an exception to the policy for one child, they would have to help many others in the same situation. He agreed, and gave her the authority to decide on a solution. Working with other government officials during a long weekend meeting, Dr. Davis came up with a way to allow the Secretary to grant a special exception to Katie and, at the same time, developed a process that would allow others to receive the same benefit.

Waiver programs

At a news conference on November 10, 1981, President Reagan talked about Katie's situation—never saying her name or where she was from, but using her case as an example of how "hide-bound regulations forced the government to be inhuman." The news media went crazy. I talked to hundreds of reporters, and Katie's story appeared on all the television networks. On November 12, the Secretary of Health and Human Services formally granted Katie her exception to policy. By the next morning, 247 families had called the department asking for similar help for their own children. The answer they were given was yes—and waiver programs were born.

Katie was discharged from the hospital on December 19, 1981, amidst a flurry of family, friends and media. The path during the last 15 years has not always been easy, but it has always been worth it. Medicaid waiver programs live on in every state and currently serve more than 500,000 individuals with special health care needs. **EP**

Julie Beckett lives in Cedar Rapids, Iowa, with her daughter, Katie, 18. Julie is a program assistant with the Child Health Specialty Clinics at the University of Iowa Hospitals and Clinics in Iowa City, and serves as National Coordinator for Family Voices, the national grassroots coalition of families speaking out on health care reform for children.

For more information on waivers, call your state Medicaid director. The address for Family Voices is P.O. Box 769, Algodones, NM 87001.

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—"Editorial," October 1989

Chris got the job on _Life Goes On_ by himself. He wrote [a] letter to Jason Kingsley when he saw Jason on TV. It was Jason's mother, Emily, who picked up on it and wrote back...

—Marian Burke in "Real Life Goes On," October/November 1991

OCTOBER 1989

SESAME STREET

Modeling a World That Respects Every Child

by Emily Perl Kingsley

Deaf actress Linda Bove, signing the word "friend" with a Muppet buddy, first appeared on *Sesame Street* in 1971 as part of the Little Theatre of the Deaf. She has been a regular cast member for almost 20 years. Photo: Richard Termine.

In 1970, *Sesame Street* was a very young television program, only in its second season. And I was the show's newest, youngest writer. So when we heard about the Little Theatre of the Deaf (LTD)—an innovative company of actors doing imaginative, exciting material for children—*I* was the one assigned to make the trek out to an elementary school on Long Island to attend a performance and check them out.

I was, of course, totally enchanted. I rushed back to *Sesame Street* and enthusiastically encouraged the producers to incorporate some LTD segments into the show. Those segments, which aired later that year, utilized a combination of sign language and spoken language along with the marvelous acting and pantomime talents of LTD's deaf and hearing actors. Those episodes marked the very first appearances of individuals with disabilities on *Sesame Street*—and a small sample of the remarkable scope and range of integration that was to follow!

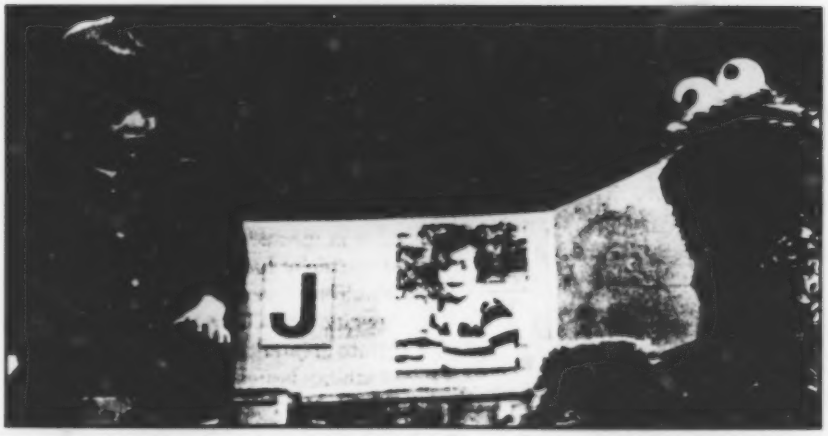
Beginnings

LTD and Linda Bove, a deaf LTD actress, appeared several times a year during the next few years. Audience response to Linda was so positive that the show's producers invited her to become a regular cast member. Linda has been with the show ever since. Through her appearances on the show, as well as in *Sesame Street Magazine* and *Sesame Street* books, Linda has introduced many millions of children to the beauty of sign language and to the dignity and integrity of the deaf life experience.

I was assigned to write many of those early segments featuring Linda and LTD. In researching those first assignments, I needed to learn to sign so I could begin the process of getting to know the actors. Those were my very first attempts to establish personal relationships with people who had disabilities. Those friendships began to educate, sensitize and politicize me.

An idea arrives with the fan mail

Around that time, a remarkable letter arrived in the *Sesame Street* "fan



Three-year-old Jason Kingsley shows Cookie Monster his letter identification skills in a 1977 episode of *Sesame Street*. This segment was one of the earliest media representations of a young child with Down syndrome demonstrating academic skills, proving that he was mastering the necessary skills for reading. "This was groundbreaking material at a time when children with Down syndrome were largely presumed to be uneducable," writes his mother, Emily.

Where's Jason now? *For an update to Jason's story, see page 54.*

mail." It was from the mother of two children: a six-year-old with Down syndrome and a three-year-old who did not have a disability. Each day, this mother sat both of her children in front of the television set to watch *Sesame Street*, assuming that the younger child would be educated and the older one entertained. (Remember, in those days we didn't know all that much about the academic potential of kids with Down syndrome.) "Imagine my surprise and delight," she wrote, "when one day, my older child—the one with Down syndrome, the one *not* expected to learn from the show—looked up at me and recited the alphabet, not once, but *twice!*"

That letter was a revelation to all of us. We suddenly realized that the age range to which our curriculum content was geared (approximately 3–5 years) really meant a certain cognitive level rather than a specific chronological age. We began discussing the idea of including material for older children who might be considered "slower learners," but who were ready for our curriculum. Then, we also began to think about actually including some of these children on the show. Perhaps, we thought, kids without disabilities in our audience could benefit by learning to accept their peers who might learn more slowly or need additional help.

Children like my child

As I was working on the development of this new show material, I became pregnant. In June 1974, my son, Jason, was born—with Down syndrome.

Overnight, my academic interest in disability issues became intensely personal. Suddenly, I was struck by the absolute and total *absence* of children like mine in the media. Everyone on television looked so "perfect," so very—the word still catches in my throat—"normal." I looked at television programming, advertising, catalogs, illustrations in magazines; the media was not depicting *my* experience at all!

It was as if my child and I had instantaneously fallen off the face of the earth. We had, in fact, just joined America's largest minority group, but as far as the media was concerned, we were insignificant to the point of invisibility. It was a terrible feeling—a feeling of isolation, of alienation, of hurt and pain at society's total disregard for the integrity and value of my precious son.

Suddenly, the inclusion of children with disabilities—children like *my* child—on *Sesame Street* was an issue of profound personal importance. Fortunately, all the people at *Sesame Street* were being sensitized at the same time. Everyone was in agreement, totally committed to the principles of full inclusion, and specific efforts to integrate the show increased in earnest.

Frequent, comfortable exposure

The results of those efforts have been impressive. Through the years, both children and adults with disabilities have appeared regularly on *Sesame Street*. In one episode, Itzhak Perlman and a youngster

continued on page 77

Sesame Street Magazine shares the television show's commitment to the inclusion of individuals with disabilities. The magazine has featured specific articles about disability and also incorporates people with disabilities within the regular illustrations whenever possible. In this illustrated feature on children's games, from the June 1994 issue, a girl with a disability is shown as just another child at play (illustrations by David Prebenna/© Children's Television Workshop). The *Parents' Guide*, which accompanies each issue of the magazine, has included articles about parenting children with disabilities, inclusion, sibling concerns and other related topics.

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In 1993, Tarah Lynne Schaeffer, 11, became a regular member of the *Sesame Street* cast. Tarah, who has osteogenesis imperfecta, uses a wheelchair for mobility. Some of Tarah's appearances on the show have focused specifically on such disability-related topics as her wheelchair racing activities, ramps, adaptations that can allow her to participate in games and the accommodations necessary to permit her to have an ordinary sleep-over with a friend. But many other segments show Tarah as just another resident of *Sesame Street*, doing exactly the same activities as everybody else. Photo: Children's Television Workshop.

continued from page 75

with spina bifida discussed the architectural and attitudinal obstacles they encounter every day. In another, Ray Charles talked about what it's like to be blind. In yet another, a young girl helped her father prepare to compete in a wheelchair race.

Many such segments provided young viewers with specific information about aspects of various disabilities, including guide dogs, architectural accessibility, Braille, wheelchairs and sign language. Other segments—and these are my favorites—simply incorporated people with disabilities into the ordinary, everyday activities of life on *Sesame Street*, without drawing any particular attention to the disability. The wonderful segment entitled "Katie and the Baby," for example, just dealt with the experiences of a big sister on the birth of a younger sibling. That the big sister had Down syndrome was never mentioned.

Kids with a variety of disabilities have appeared as ordinary members of the *Sesame Street* community or in short films targeting specific curriculum goals. My own son, Jason, has appeared in many curriculum-related segments performing a variety of academic skills—everything from identifying letters of the alphabet to counting in Spanish. As a matter of course, the show's producers now make sure that children with disabilities are cast in *any* film showing groups of kids and that they are shown doing the same activities as everyone else.

Such segments carry strong messages to our viewing audience. Children with disabilities are pleased and proud to see other children like themselves represented on television as fully participating members of the community. Siblings are also reassured by seeing kids like their brothers and sisters on the show. And the great audience of kids (and their parents) without disabilities has a chance to see children with disabilities who can perform and achieve, children who are potential friends. As we in the disability community know, this kind of frequent, comfortable exposure can eliminate feelings of strangeness and fear and lead to better understanding and acceptance.

The best endorsement

The public response to the show's years of comfortable natural inclusion of folks with disabilities has been wonderful and gratifying. The show has won many, many awards. We've also received thousands of letters from grateful parents. But the best endorsement of all comes from the kids in the audience. Our research department happily reports that children surveyed after watching specific disability segments demonstrate greater comprehension of disability issues and of the essential similarities of feelings and experiences shared by all children.

I am extremely proud to have written many of the "disability segments" for *Sesame Street* during the past 26 years. But it is the real and sincere commitment to those principles shared by all the other writers and, in fact, every member of the show's staff and crew that makes me so grateful and proud to have been associated with *Sesame Street* and Children's Television Workshop for all these years. I am confident that as long as *Sesame Street* exists, it will continue to model a world in which *all* children are understood, accepted, cherished and respected. **EP**

Emily Perl Kingsley has been writing scripts for Sesame Street *for 26 years and has won 11 Emmy Awards. The mother of Jason Kingsley, 21, who has Down syndrome, much of Emily's other work revolves around efforts to enhance the understanding and acceptance of individuals with disabilities. Her CBS Movie of the Week,* Kids Like These, *starring Tyne Daly and Richard Crenna, dealt with her family's experiences raising Jason. Emily was proud to be the dictation typist for Jason Kingsley's and Mitchell Levitz's book* Count Us In: Growing Up With Down Syndrome, *now in its fourth printing and available through Exceptional Parent Library.*

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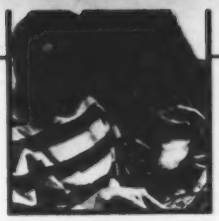

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In April, an aunt of one our viewers called to tell us that her nephew had died. Jake was 24 years old; he'd had multiple disabilities all his life. In that tearful phone call, Jake's aunt said that his whole family felt close to our Neighborhood because of Jake's involvement with us. In a way, we had become part of his extended family… a part of *their* neighborhood.

Some families have written about specific ways they have used what we offer, like this parent, who wrote, "My son, Blake, is seven years old and has been blind since birth. Because he can-

continued on page 80

A Visit With Jeff

Ten-year-old Jeff Erlanger appeared on MISTER ROGERS' NEIGHBORHOOD in an episode that first aired in 1980. The following is an excerpt from Jeff's conversation with Mister Rogers:

Mister Rogers: [looks at the camera and addresses his television audience; beside him is a young boy in a power wheelchair.] This is my friend, Jeff Erlanger. He's one of my neighbors here, and I asked him if he would come by today because I wanted you to meet him, and I wanted you to see his electric wheelchair. [Turning to Jeff] We've been talking about electric cars and all kinds of electric things this week. Would you show me how you make your chair go?

Jeff: OK, sure! [Jeff's fingers, wrapped in a metal brace, touch a lever.] Well, first, this is the on and off switch, and I move this to turn it on. And… [Jeff moves the switch as the chair backs up, turns around, goes forward, rounds the corner, turns around and returns.]

Mister Rogers: You're really good at that.

Jeff: Thanks.

Mister Rogers: That's a very fancy machine.

Jeff: Thank you.

Mister Rogers: But you're the one who makes it go!

Jeff: Correct.

Mister Rogers: Did it take a long time to learn how?

Jeff: No, not really. I have had other wheelchairs. My first electric wheelchair only took me about a day to learn to use.

Mister Rogers: Gee, that's wonderful! Jeff, your mother and dad must be really proud of you.

Jeff: [nods and smiles] I'm sure they are.

Mister Rogers: Well, I know I am. Can you tell my friends what it is that made you need this wheelchair?

Jeff: Sure. Well, when I was about seven months old, I had a tumor, and it broke the nerve that tells my hands and legs what to do. And they tried to cut the tumor, but they couldn't get it, and I became handicapped. And I got a wheelchair when I was four years old…

Mister Rogers: You must have some mighty good doctors who've been taking care of you… Can you tell me any of your doctor's names?

Jeff: Yeah, I have a pediatrician, Dr. Henson, who works in St. Mary's Hospital. Then, at U.W., the bone doctor is Dr. Reed, who takes care of… [Jeff hesitates] the bones, I guess, 'cause he's a bone doctor! Anyway, I had surgery earlier this summer. I had a pain in my stomach called autonomic dysreflexia and…

Mister Rogers: What was that?

Jeff: Autonomic dysreflexia. I'm not sure what it means.

Mister Rogers: But you sure can say it.

Jeff: Yeah! [Jeff smiles] Anyway, so I had surgery done just recently to try to cut the sphincter holding my urine in… So I have a lot of things going on in here, which just shows you that you have a lot of things happening to you most of the time when you're handicapped. And sometimes that happens when you're not handicapped.

Mister Rogers: But you're able to talk about this so well.

Jeff: Yeah.

Mister Rogers: And help other people who might have the same kind of things.

Jeff: Uh-huh.

Where's Jeff now? *For an update to Jeff's story, see page 58.*

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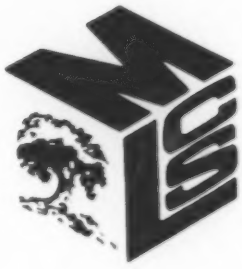

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Circle #108

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not see, television means very little to him. But there is one show he has listened to faithfully since he was about a year and a half old, and that, of course, is *Mister Rogers' Neighborhood*.

"In addition to his blindness, Blake has epilepsy and a hearing loss. As I am sure you can imagine, he has felt a tremendous amount of frustration, anger and pain during his short life. When he has had a particularly trying day, I frequently hear him stomping around the living room singing [your song], 'What do you do with the mad that you feel?' at the top of his lungs. I truly believe you have helped this child learn to deal with his frustration and anger at the lot life has dealt him."

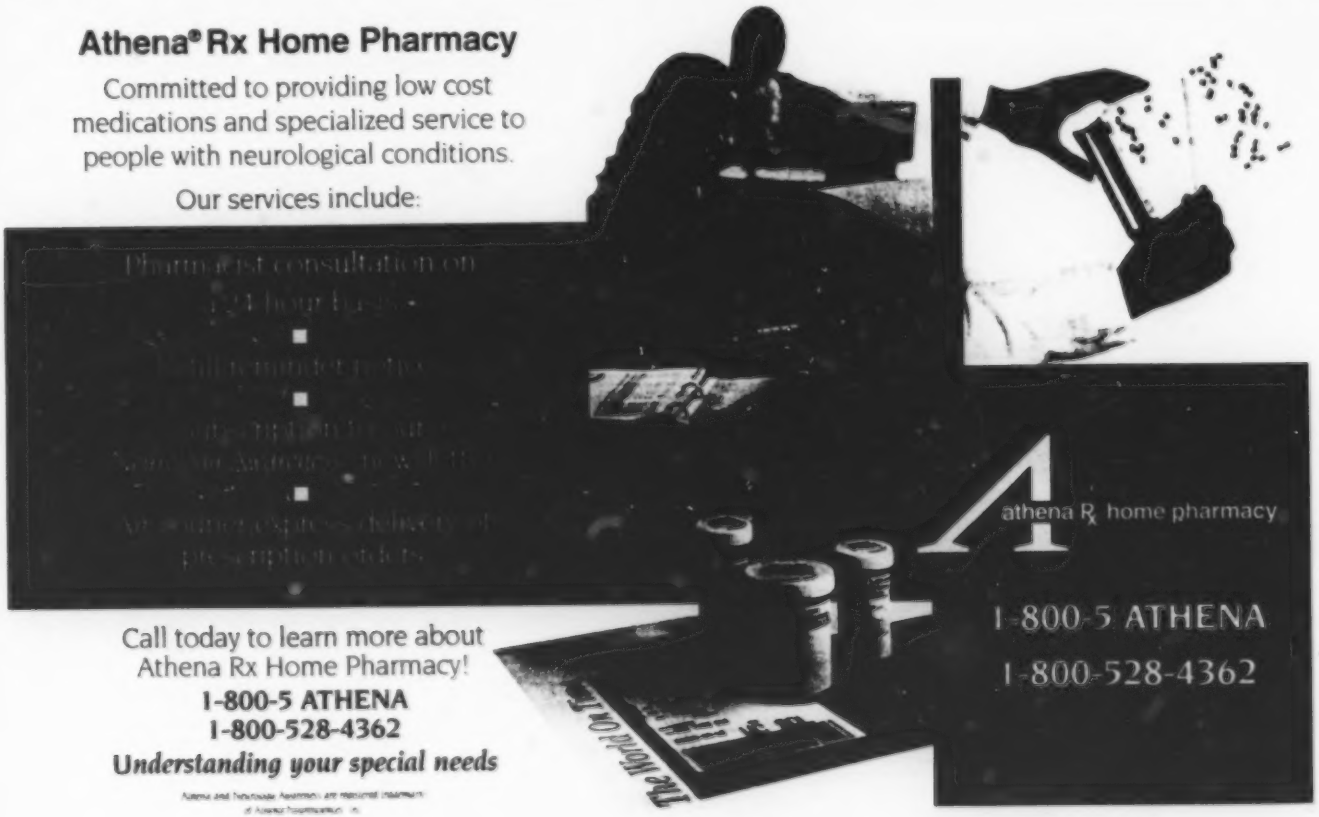
Fred Rogers and Chrissy Thompson, 10, share a storybook on an episode of *Mister Rogers' Neighborhood*. Chrissy, who has spina bifida, and her older sister, Terri, played the grandchildren of neighborhood residents Mr. and Mrs. McFeely. The Thompson children were regulars on the show in the mid-1970's.

Visiting with Jeff

One of our most treasured times in the Neighborhood was a visit with Jeff Erlanger, a remarkable 10-year-old boy with multiple disabilities. The program that features Jeff's visit is now part of a select group of programs that repeats each year. Although it was filmed almost 15 years ago, our conversation and the things I learned from Jeff that day are as relevant today as they were then.

Jeff and I talked a bit and sang together, "It's You I Like," and then shared some thoughts about times we have both felt sad and happy. Then, after Jeff rode off in his wheelchair, I went back into the house and sat on the floor. As I cleaned up the blocks I had been building with earlier, I said to my television friends, "I was just thinking, for all Jeff's physical problems, he's such a competent boy. He has learned so much because his mom and dad love him, and he loves them. They've learned together. That's what learning is all about, isn't it? A lot of it has to do with love. Jeff is certainly able to talk about his worries. He's able to talk about anything. It's really great to have a friend like that."

Jeff is now a 24-year-old college student majoring in political science. We've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stayed in touch with Jeff and his family, and we've shared their pride in how well Jeff and his sister are growing.

Catching attitudes

Although television is a form of "mass communication," that doesn't mean it isn't personal. In fact, I've always felt that television is uniquely effective because it *is* personal. We form relationships with the people we care about on television. We come to feel we "know" them. Because of this, viewers take even more away from television programs. There's an old Quaker saying, "Attitudes are caught, not taught." When children feel a caring relationship with the person on television, then they're likely to "catch" that person's attitudes about people—attitudes such as compassion, caring, empathy and acceptance.

People have written over the years to tell us what they've "caught" from times like that. One of our favorite letters came from two Stuyvesant High School (New York City) seniors who asked us for a letter to publish in their yearbook. They wrote, "You were one of our first teachers, who taught that everyone is different and that you liked us for who we are.... We want you to know what an impact you have had on us; we will always be individuals who judge others by what's inside."

I am proud of those young people, who obviously must feel good about themselves in order to hear those kinds of messages and to want to use them when they meet someone who may seem different at first, someone who may have a disability.

Finding inner strength

During an upcoming week of Neighborhood programs on the theme "Be Brave and Strong" (August 26–30, 1996), we meet up with our good friend, Eric Kloss. Eric is a jazz saxophonist who is blind, and he's visited our Neighborhood a number of times. After feeling nourished by the music he made with our Neighborhood musicians, I thought about the many ways Eric has had to be brave and strong throughout his life. I'm sure his courage has come from the support he's had from his family and friends.

Supporting people and helping them find their own inner strength has always been part of the very personal messages of *Mister Rogers' Neighborhood*. In the same way, I would venture a guess that the families who read EXCEPTIONAL PARENT grow in strength and courage from the writings they find here. Like our Neighborhood visits, magazines also

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Circle #21

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are a part of "mass media," but they can offer something very personal when they come from real people willing to share their real stories—their strengths as well as their vulnerabilities.

EXCEPTIONAL PARENT is a source of support for the families who read it. It offers comfort, "visits" with others who share similar concerns about their children, a safe place to grieve for the dream that might have been, information, hope and acceptance of everyone for who they are—as parents and as human beings.

All of us here in our Neighborhood send our warmest wishes for EXCEPTIONAL PARENT's 25th year and for all that is ahead for the magazine—for your staff and for your readers. In a "magazine" way, EXCEPTIONAL PARENT says to all families, "*You* are special, too." **EP**

Fred Rogers' career began with NBC radio in 1951, following his graduation from Rollins College with a degree in music composition. In 1953, Rogers moved to Pittsburgh to work at WQED, the nation's first community-supported public television station. There he served as producer, musician and puppeteer on a daily one-hour children's program, THE CHILDREN'S CORNER. In his free time, Rogers attended the Pittsburgh Theological Seminary and studied child development at the University of Pittsburgh. He was ordained as a Presbyterian minister in 1962, with a charge to continue his work with children and families through the media.

In 1966, Rogers began working on the development of a new half-hour children's show; MISTER ROGERS' NEIGHBORHOOD was first distributed nationally in 1968. The show, which still airs daily, is the longest-running program on PBS. Fred Rogers and the show have received virtually every major award in television and dozens more from special-interest groups in education, communications and early childhood.

Rogers lives with his wife of 44 years, Joanne. The couple has two married sons and two grandsons.

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25 Years of Accessible Television

by Kristen White

Rugrats is captioned by The Caption Center for Nickelodeon, with funding provided by the U.S. Department of Education.

The amount of currently available closed-captioned television programming boggles the mind. All prime-time network programming, most network late-night and daytime programming, an increasing amount of cable programming and hundreds of music videos and commercials—yet none of this was available just 25 years ago.

In 1971, the same year that EXCEPTIONAL PARENT published its first issue, the WGBH Educational Foundation in Boston established The Caption Center with the purpose of devising a way to make television accessible to the nation's more than 20 million deaf and hard of hearing viewers. One year later, television's "silence barrier" was broken when Julia Child's *The French Chef* debuted on PBS with open captions, that is, captions visible to all viewers.

Soon thereafter, The Caption Center began producing *The Captioned ABC News*, the first nightly television news program accessible to deaf and hard of hearing viewers. Each night's captioned newscast was the same program that had aired earlier in the evening, without captions, on ABC. Following that first broadcast, captioners at The Caption Center worked to insert open captions on the tape for rebroadcast later that same night on more than 190 PBS stations.

In the late 1970's, PBS engineers developed technology to allow the broadcast of *closed* captions, captions hidden in the video signal but visible to anyone with a special decoder. Congress then allocated funds to establish the National Captioning Institute (NCI) to produce closed captions and to manufacture and distribute decoders. The Caption Center also continued to produce captions. As more viewers began to enjoy and rely on the technology, the broadcast industry increased its commitment to providing accessible programming. By 1989, all commercial network prime time (8–11 p.m.) programming aired with closed captions.

Legislation leads to more captioning

Many consumer organizations, captioning agencies and legislators worked together to bring about the Television Decoder Circuitry Act of 1990, which requires built-in closed-caption decoders in all U.S.-sold television sets with screens 13 inches or larger. The Electronics Industries Association (EIA) estimates that 29 million new decoder-equipped televisions are sold each year and that every home in the country will have at least one decoder-equipped television by 2000.

The ready availability of decoding technology has increased the potential audience for closed-captioned programming. It's not just deaf and hard of hearing people now watching captioned shows; increasingly, caption viewers include people learning English as a

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Accessible Television for People with Visual Impairments

According to the American Foundation for the Blind, individuals with visual impairments "watch" the same amount of television, on average, as sighted people. Since 1990, Descriptive Video Service (DVS) has been making television more accessible to this population as well.

DVS adds narrated descriptions of the key visual elements of a program or movie—actions, scene changes, costumes and body language. These descriptions are inserted during pauses in the dialogue and can be heard through the second audio program feature (SAP) on any stereo television set or VCR. DVS programming is currently available on more than 130 PBS stations and on 140 popular video releases available for mail-order purchase or free loan at many public libraries. Sixteen titles can also be rented at certain Blockbuster Video outlets, and films with DVS are now airing regularly on Turner Classic Movies, a cable network.

To receive a free DVS programming guide, mail-order catalog of DVS videos or more information on any DVS service, call (800) 333-1203.

—*Vita M. Longo*

Vita M. Longo is the marketing manager for Descriptive Video Service, a nonprofit division of the WGBH Educational Foundation in Boston, Massachusetts.

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second language and children and adults learning to read.

The Decoder Act specifications for built-in decoder chips added some important new features by supporting color captions, text mode and the full (upper- and lower-case) character set. This makes it more feasible, for example, to provide captions in several alternate languages and reading levels. These new features will be phased into general use over the next several years.

Likewise, the Telecommunications Act of 1996 will have far-reaching effects on the way television is delivered to our homes, schools and offices. This legislation includes provisions that mandate captioning of all television programs unless the cost would be "economically burdensome." Based on comments solicited from consumers, captioning agencies, networks and television industry organizations, the Federal Communications Commission (FCC) is expected to recommend new captioning regulations by August 1997.

The captioning industry

Closed captioning is underwritten by a combination of public and private funding sources. The Department of Education (DOE) awards grants, called cooperative agreements, to captioning agencies. Agencies use these awards as seed money to build a shared responsibility for the cost of captioning within the private sector—commercial networks, producers, syndicators and advertisers. DOE grants are awarded in seven programming areas: syndicated programming, movies, miniseries and specials, national news, daytime programming, sports and children's programming. Six captioning agencies now provide most of the closed captioning at the national level: The Caption Center and NCI are nonprofit corporations; VITAC, Captions, Inc., Media Captioning Services and Real-Time Captions, Inc. are for-profit companies.

The caption industry still faces many challenges, including developing methods to make multimedia (such as CD-ROMs and digital video disks) accessible and assuring that captioning will be compatible with the advanced television systems of the future. We look forward to working with consumers and the television and multimedia industries to achieve even greater access milestones in the months and years to come. **EP**

Kristen White is the consumer affairs coordinator at The Caption Center, in Boston, Massachusetts. For more information, contact The Caption Center at (617) 492-9225, V/TTY, or on the Web at http://www.wgbh.org/caption.

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1971-1996

Watching a child... master independent mobility in a lightweight or power wheelchair is a happy event. I have gotten misty-eyed watching young wheelchair jockeys take off to play with their friends...

—"Taking Control of Purchasing a Wheelchair" by Jan Little, March 1991

The energetic skier on our cover... symbolizes the dramatic ways in which the mobility of children with disabilities has changed in recent years—from a relatively passive seat as a spectator to active, mobilized participation in everyday family and community life...

—"Editors' Desk," March 1991

MARCH 1991

MOBILITY

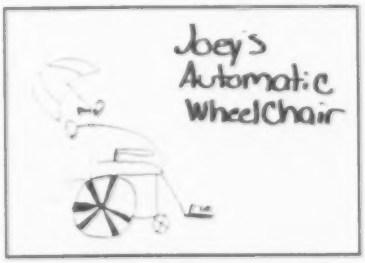
A Glance at the Past, a Glimpse of the Future

by Naomi Angoff Chedd

In 1920, there were few wheelchair options for children or adults... Photo courtesy of the Cotting School, Lexington, Massachusetts.

Twenty-five years ago, wheelchairs cost a few hundred dollars. You were hard-pressed to find one in colors other than black and chrome or one that weighed less than 60 pounds. As a rule, seats were 16 inches deep and either 16 or 18 inches wide. Maybe you had a choice between two types of armrests, but it was virtually impossible to find any that were adjustable or removable. There were no chairs designed specifically for children, just scaled-down versions of adult-sized chairs. The concept of positioning didn't exist; pillows and rolled-up towels could be used for comfort. Height wasn't adjustable, and there were no swing-away footplates. Tilt-in-space chairs? Standing chairs? Are you kidding?

Power wheelchairs did exist 25 years ago, but, as one user put it, "My chair was in the shop more often than my neighbor's Fiat." They were loud and heavy, and had to be recharged after a trip to the corner store. "'Clunky,' 'awkward' and 'user-unfriendly' are the words that come to



My wheelchair of the future has built-in shoes on the footrest. It has a microphone that my teacher can talk into, and then it will go wherever she says. It will be red and go very fast.

—Joey Padula, 13

mind when I think about the past," says Brian Rourke, national sales manager for one wheelchair manufacturer. "Back then, clients had to fit the chair. Now, it's the other way around."

More and more choices

Today, parents and children have a wide range of mobility choices. Wheelchairs have become smaller, lighter and more attractive, and offer dozens of seating and positioning options. Purchasers can rely on highly skilled people who know how to put the right components together so just about any child can sit comfortably and, if able, propel a chair either manually or with one of the many types of electronic switches.

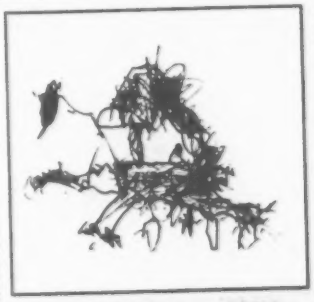
Wheelchairs can be equipped with a variety of seats, backs, armrests, headrests and footplates. A fully customized seating system that fits the needs of an individual child can be designed using computer-aided body analysis. Power chairs of many shapes and sizes are readily available. Although some parents and children say they are still too heavy and cumbersome, power chairs provide mobility and independence for thousands of children who, in the past, would have had to depend on someone else to get them from place to place.

Those sleek, quick-folding, ultra-lightweight sports chairs didn't exist a few decades ago either. Now, a number of manufacturers make them, enabling more kids than ever to participate in sports and fitness activities.

Making a fashion statement

Technical changes aside, perhaps the greatest innovation in wheelchair design—at least as far as most children are concerned—has been color. "Suddenly wheelchairs became cool," says John Winske, director of the Massachusetts Coalition of Citizens with Disabilities and a wheelchair user for more than 20 years. "Finally, wheelchairs were getting away from that medical, orthopedic look."

In fact, wheelchairs have become a source of personal expression, even pride. Winske points out that children, especially very young children, weren't seen driving power chairs in the old days. "Now little kids, even toddlers with disabilities, can explore and control their environment, just like any other child. Power chairs provide an opportunity for much more normal development," he stresses.



My wheelchair of the future is a rocket-powered megachair. It goes faster than ordinary chairs, and the rocket fuel never runs out. An ordinary electric wheelchair joystick will make it go. There is a dome on top that bugs and birds cannot penetrate. There are waterproof electronics everywhere, including surround sound for a stereo system. Inside the dome, there's a climate control unit.

—Michael Gaglione, 18

Positioning: an important new field

"There was no such thing as seating and positioning 25 years ago. Now, positioning is as important as the chair itself," says wheelchair designer Tom Whelan. He believes that societal change was a crucial component in producing the variety of wheelchairs available today. Over the last few decades, Whelan explains, more children with disabilities have been raised at home, sent to neighborhood schools and included in all aspects of community life. So parents and professionals have pushed for wheelchairs and strollers that make kids feel more comfortable and look good. "Fortunately," he adds, "this change in attitude gained strength in the 1970's, at a time when technology was moving fast.

"The issue with kids used to be one of 'management.' We used to ask, 'How do we put the child in it, and how are we going to make it move?' Now we see wheelchairs as therapeutic. We now realize that proper positioning can actually improve posture and alignment, and, in some cases, give children a chance to stand or even walk later on."

Whelan believes that the impact of a disability can be minimized with better positioning. "If a child looks and feels good," he continues, "everything improves. A comfortable, confident child can learn and socialize in a more natural way."

When Save-A-Step, predecessor to the Braun Corporation, first began manufacturing wheelchair lifts in 1970, each lift was designed for a specific vehicle model and was assembled piece-by-piece.

Then, in the 1980's, Braun created a system of interchangeable parts that could be mixed and matched to suit many needs. This meant that one basic lift could now be easily adapted for use in roughly 150 different vehicles. (Photos courtesy of Braun Corporation.)

continued on page 58

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Chairman Robo

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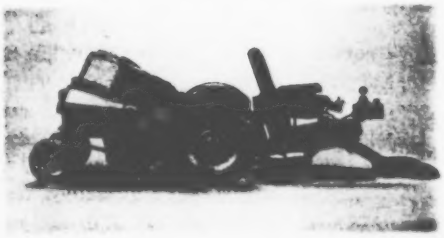

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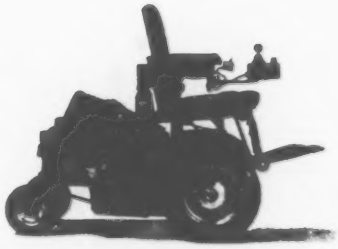

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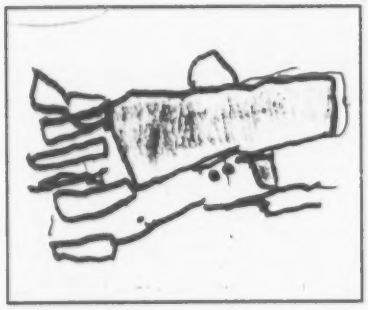


My wheelchair can go on snow, and it has a steering wheel. My wheelchair can fly. It has six jet-powered motors in the back. It can seat one person.

—Kevin Hatch, 10

continued from page 87

Scooters gaining in popularity

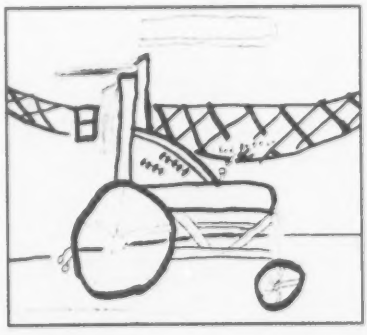
Scooters were around in the 1960's, recalls Bob Boyd, product designer, "but they looked like some kind of backyard project... The seats were molded plastic, like something you'd find in an airport waiting area, and nobody thought about customization."

The earliest scooters had only three speeds. Now, they move faster and more smoothly. "Most physicians and therapists wouldn't have dreamed of putting a child in a scooter a couple of

continued on page 90

My wheelchair of the future is a rocket booster chair. I go over all the snow banks and up hills—I only have to press the red button. My chair has a sunroof, air conditioning and a water cooler for the summer. It has a bag on the sides for books or money. It has surround sound for a radio and CDs.

—Jennifer Evers, 20



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25th Anniversary
1971-1996

continued from page 88

decades ago," Boyd says. But today, scooters are gaining in popularity, particularly for children and young adults who have good upper body control and those who can do some walking but need relief from fatigue or want to keep up with friends. "They are also popular for individuals with dwarfism," he adds. "Scooters not only provide mobility, but they also put smaller people at eye level with their taller peers, which enhances social interaction."

In addition, today's scooters come in at least half a dozen colors, have better tires and switching devices, and are easier to maneuver. New innovations of the last five years include four-wheeled scooters and joysticks for steering.

Scooter designers are increasingly using lighter-weight materials and modular designs to make them easier and faster to assemble. Boyd predicts that as the population ages, scooters will probably grow in popularity. Scooters will become more efficient and more available as demand grows. This is good news for children with disabilities, and for their parents, too.

"However," Boyd cautions, "insurance companies are still more willing to pay for wheelchairs than for scooters. They need to be educated. Scooters are often a medical necessity and usually cost a lot less than chairs."

Regal pediatric scooters are manufactured by Bruno Independent Living Aids. The company began manufacturing pediatric scooters five years ago. (Photo courtesy of Bruno Independent Living Aids.)

Mobility of the future

What technological changes lie ahead? Are there devices in the works that will allow children with severe motor limitations to use power mobility for the first time? What will mobility devices of the future look like?

Most designers and manufacturers predict that wheelchairs and other mobility devices will become sleeker-looking. More companies will manufacture modular components so wheelchairs can be assembled faster, and they will be made from lighter-but-stronger composites and exotic materials. Batteries will become more efficient and require less frequent charging.

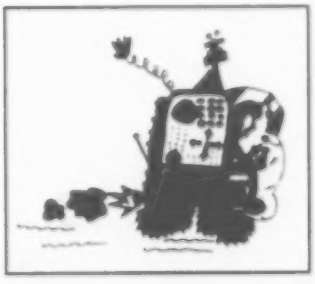
It's also likely that mobility devices will become more customized to individual needs that are not yet being met. For example, voice- or sound-controlled wheelchairs may be more readily available in the future. Built-in augmentative communication devices and environmental controls may also be available, and robotics may be used for steering. The next 25 years may even bring alternative mobility systems—systems without wheels.

One concerned professional believes that the people who provide assistive technology will have to adhere to higher professional standards and be credentialed and more accountable than at present, "so that more end users get exactly what they need at a reasonable price."

The more children and adults with disabilities become integrated into schools and society, visible and active in their communities, and vocal in business and government, the more potential there will be for change and improvement in the mobility industry. The result will be a truly innovative and demand-driven market. **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT'S *editorial staff. Zoey Bailey, Jennifer Evers, Michael Gaglione, Kevin Hatch and Joey Padula, "wheelchair of the future" authors/artists, are students at the Cotting School in Lexington, Massachusetts.*

Thanks to the following people for their contributions to this article: Bob Boyd, Bruno Independent Living Aids, Oconomowoc, Wisconsin; Laura Bumpers, R.P.T., Massachusetts Hospital School, Canton, Massachusetts; Bob Clarke, Everest and Jennings, St. Louis, Missouri; Jan Little, assistive technology consultant, Chicago, Illinois; Elmer O'Brien, Permobil, Woburn, Massachusetts; Brian Rourke, Vector Mobility, Fresno, California; Tom Whelan, Quickie Wheelchairs, Fresno, California; and John Winske, Massachusetts Coalition of Citizens with Disabilities.



My wheelchair of the future is an electric wheelchair with a camera so I can see behind and on the sides using a television screen that is also a regular TV. It has bulletproof and weatherproof glass windows. It is equipped with a microphone to be heard outside of the bubble. Shelves are located in the back for storage. There is a spring hand to press the buttons on the side. The buttons operate the phone and the many other accessories needed for school. A boom box is on the side. It has dual tires so I will never have to stop to repair flat tires. It is also equipped with a head pointer to push buttons in the cockpit.

—Zoey Bailey, 16

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COMMUNICATION

Augmentative and Alternative Communication

by Barry Romich

Augmentative and alternative communication (AAC) has had a significant impact on many of the same people whose lives have been touched by EXCEPTIONAL PARENT. As we celebrate 25 years of EXCEPTIONAL PARENT, we can also celebrate a quarter century of technological innovation in the field of AAC.

Low-tech solutions

In 1971, the communication needs of people who could not speak were met primarily through low-tech methods:

- *Communication boards* with letters or symbols to which individuals could point manually were the most common AAC devices.
- *Electric typewriters* became another commonly used AAC device. Their popularity led to the development of several different controls for individuals who did not have the motor skills to depress keys on a standard typewriter keyboard. These included expanded keyboards, sets of switches, or single-switch-operated scanning light arrays. The latter technique, which came to be known as row-column scanning, organized letters into rows and columns, each with a corresponding lightbulb. First, each row of letters would light up. When the row containing the desired letter was lighted, the user hit the switch. Then the lights would go on, one at a time, across that row until one was selected and typed.
- *Clockface pointing systems* used pictures, symbols or printed words pasted on a clockface in place of the numbers. When an activating switch was pressed, a motor turned a pointer that looked like the second hand of a clock. Deactivating the switch stopped the pointer at the selection of the user's choice. Later configurations replaced the motor with lightbulbs that turned on sequentially, each indicating a new selection. This general technique came to be known as linear scanning.

1969

The Prentke Romich Company, established three years earlier, built their first communication system. The user needed a range of motion of several inches with one hand to reach eight microswitches built into a lapboard and connected to a huge teletype machine of the type commonly discarded by the telephone company. Sequential presses of two switches would type a single letter. For example, the letter "A" might require pressing switch 1 followed by switch 2, while pressing switch 1 followed by switch 3 might type a "B."

1971

The Tufts Interactive Communicator (TIC) was developed at Tufts University as a student project for an engineering course. Its creator was Rick Foulds, now director of the Rehabilitation Engineering Center at the A.I. duPont Institute. The TIC used a row-column scanning system that could be operated with a single switch. The output consisted of letters that appeared on an alphanumeric display.

The photo at the beginning of this section shows, 10-year-old Charles Fleisch, who has cerebral palsy, using one of the approximately 150 TIC units that were produced and distributed on a non-profit basis during the 1970's.

1975

The Auto-Com, developed at the University of Wisconsin became the first commercially available AAC device to use a microprocessor. Microprocessors, the electronic component at the heart of today's personal computers and virtually every other electronic information handling system, follow programmed instructions and manipulate information.

Auto-Com users slid a handheld

continued on page 97

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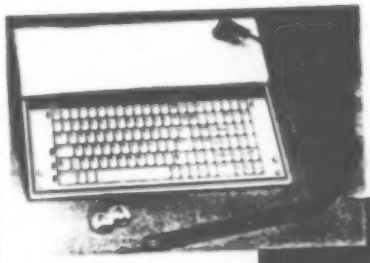

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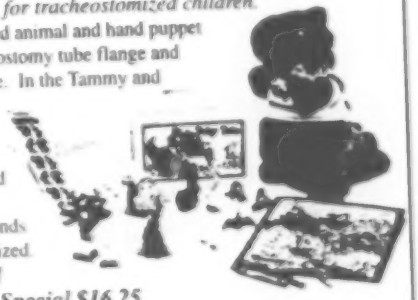

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Making Telephone Communication Accessible

In 1963, Dr. Robert Weitbrecht (right), a deaf scientist, created an acoustic coupler modem that allowed two Western Union teletype (TTY) units to transmit signals to each other over ordinary voice-grade telephone lines. It was an invention that opened up the world of telephone communication to people with hearing and speech impairments for the very first time. As AT&T, Western Union and other communications companies converted to a new telegraphic code over the next several years, older TTY models became available. Weitbrecht formed a company to manufacture his acoustic coupler for use with these surplus machines.

Many deaf people referred to these reconditioned teletypewriters as "green monsters." They were heavy and noisy; the whole house would shake with the kerplunk of each key and the shudder of the paper roll cranking out each line. But they worked. And as the surplus machines became available, telephone communication became a reality for an increasing number of people. By 1970, 870 units were in use.

During the 1970's, many manufacturers began producing telecommunications terminals that were smaller, lighter and more portable. By 1977, 27,000 units—of one kind or another—were in use. Just five years later, the number approached 100,000.

Today's TTYs are a far cry from the old green monster. The Ultratec Uniphone (below), for example, combines a TTY and standard telephone in a single, lightweight unit. Also available in many public places are pay phones with built-in TTY units.

Recognizing that typing is more time-consuming than speaking, all major long-distance telephone carriers now offer reduced long-distance rates to TTY users. And telecommunications relay services, mandated by the Americans with Disabilities Act (ADA), allow TTY users to communicate through a relay operator with people who do not have a similar unit. Relay services can also be accessed through modem-equipped computers, making them useful and attractive to many people with disabilities who can hear but do not have understandable speech.

–Kim Schive

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continued from page 92

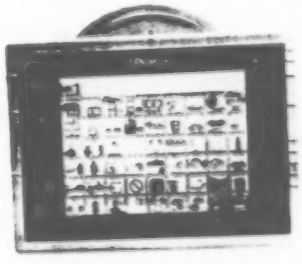
magnetic pointer across a communication board surface, activating switches located under each selection. The device was the first to permit access to whole words, phrases and sentences; users no longer had to spell everything out one letter at a time. The output appeared on a single-line electronic display, on which the user could correct mistakes before sending the text to a built-in strip printer in the upper right-hand corner of the device.

1979

Engineers at the University of Tennessee Rehabilitation Engineering Center developed the first optical head-pointing system, which used a grid of light emitting diodes (LEDs), each corresponding to a letter or symbol. Unlike incandescent lamps, LEDs could be turned on and off very fast—so fast that the entire LED array could be scanned several times a second, making the entire array appear dimly lit at all times. The user activated the system with a light sensor worn on the head and directed at the array. When the light sensor focused in on one LED, the array scanning stopped and that particular LED lit up.

The Prentke Romich Express 1 shown in the photo above used microprocessor LED control to permit the use of two selection techniques—headpointing and scanning—in a single device. This device also employed features of the TIC and Auto-Com, including user programming, word and phrase access, a correctable display and a strip printer.

Today



AAC devices are now a far cry from the low-tech solutions of 25 years ago. The DynaVox2 (left), manufactured by Sentient Systems, has a touch-screen display that leads users through a message-

continued on page 97

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CAMA: Building AAC Awareness

Today virtually every major AAC manufacturer is among the eighteen members of CAMA—the Communication Aid Manufacturers Association. CAMA's major goal is to build awareness of AAC through a program of regional, one-day workshops, typically consisting of six sessions during which CAMA member representatives make presentations. Workshops are attended by AAC professionals, parents and family members. For more information, call (800) 441-2262. The following manufacturers are CAMA members:

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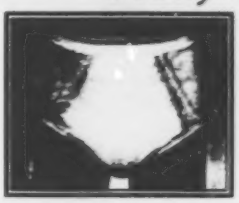

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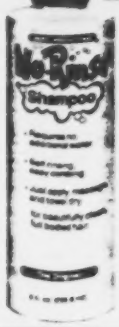

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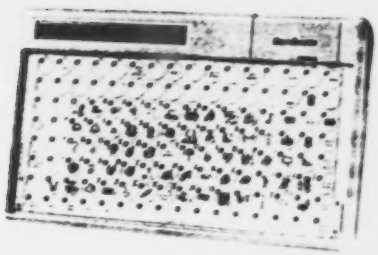
continued from page 95

formation process similar to that involved in producing typical speech. The device can be accessed through touch, with a mouse-compatible input device, or by visual or auditory scanning in combination with a switch. Users can edit and store long documents to be printed or spoken aloud. Ten voice output choices are available, ranging from child to adult in both male and female. Digitized messages can also be recorded and stored. Built-in infrared capabilities work like a remote control, allowing users to access and operate televisions, VCRs, personal computers and other applicances. (Photo and description courtesy of Sentient Systems.)

AAC IS NO LONGER ABOUT TECHNOLOGY; IT'S ABOUT LANGUAGE AND COMMUNICATION.

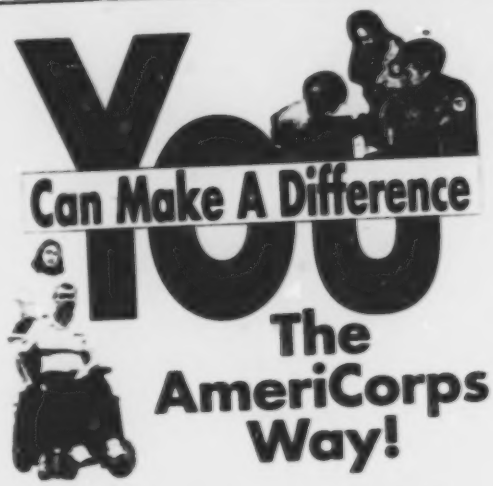


The DeltaTalker (left) is one of a range of Prentke Romich AAC devices that use the Minspeak language representation system, a system of semantic compaction in which multi-meaning icons are used to code words and phrases. This system allows users to speak thousands of words used in daily conversation with a very small set of symbols—small enough to be represented on a single, non-changing keyboard.

The future

AAC is no longer about technology; it's about language and communication. Today, thousands of people are living better lives through the use of AAC technology, but the most effective AAC users did not become so with technology alone. Technology is a tool that works only when combined with a powerful language representation method, an appropriate application program and, the support of parents and family members, speech-language therapists, teachers and friends. **EP**

Barry Romich, P.E., is chairman and CEO of the Prentke Romich Company, a long-time manufacturer of AAC devices.



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Circle #4

EXCEPTIONAL PARENT Magazine Presents

FORUM '96

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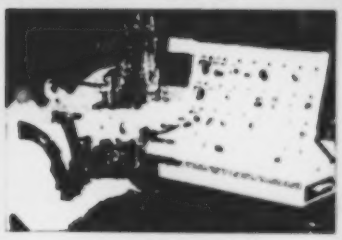
FORUM '96

"Exceptional Parent Live: A 25th Anniversary Celebration!" is the first *Exceptional Parent* conference and exhibition for parents, children and professionals. October 17-20, 1996, Anaheim (CA) Hilton, near Disneyland. For more information: call 1-800-EPARENT, Ext. 24.

579

Circle #5



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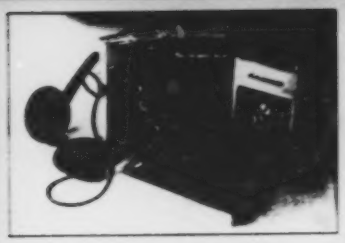

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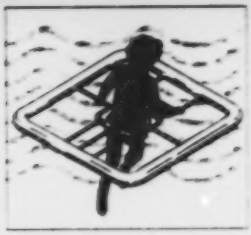
Circle #7



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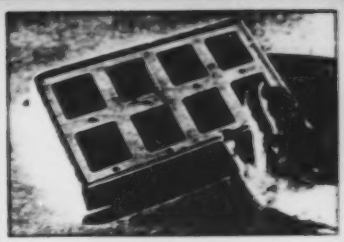
Circle #8



TOYS FOR SPECIAL CHILDREN

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Circle #15

589

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25 YEARS OF

In June 1971, the first issue of EXCEPTIONAL PARENT was distributed to several thousand parents and professionals... [E]ach issue is now distributed to 75,000 [readers]... [We] intend to celebrate our silver anniversary in every issue throughout the year—starting with this 1996 Resource Guide, our largest ever, [which] includes 10 directories containing more than 1000 resources in the United States and Canada...

—"Editor's Desk," January 1996

JANUARY 1996

Many people have asked how this magazine began and how it managed to succeed. EXCEPTIONAL PARENT's history is the story of many dedicated, wonderful individuals. Most of all, it is the story of parents of children with disabilities and individuals with disabilities who have shared their wisdom on our pages and encouraged us to continue. These people are the real experts, speaking out, supporting and inspiring one another—and us—and changing our society. They have illustrated, again and again, the power of the individual.

Our mission has always been to provide practical information to consumers. Today, parents, professionals, and children and adults with disabilities make up our vast family of readers. Our fine Editorial Advisory Board has included parents and people with disabilities for many years. From the beginning, we have collaborated with many parent organizations and encouraged readers to get involved, both to nourish themselves and to become more powerful advocates for the needs of children, young adults and their families.

Over these 25 years, we have covered a vast range of material, sometimes presenting topics rarely, if ever, covered before in a consumer-oriented publication—difficult and complicated emotions, relationships between parents and professionals, and sibling relationships when one child has a disability. Articles in these pages have advocated for education, parent organizations, day care and health insurance. We are especially proud that one of the first published articles on respite care—a service vital to so many parents today—appeared in EXCEPTIONAL PARENT in 1975. We have featured articles on sex education, recreation, single parenting, adaptive equipment, college and ways to find the time and energy for fun. We have tried to put every issue on the consumer's table with care and understanding.

In 1971, thousands of children with disabilities were excluded from school and many could look forward only to limited life choices as adults. Terms that today stand for real programs—early intervention, mainstreaming, inclusion, independent living centers, respite care, family supports, augmentative communication, the Americans with Disabilities Act, self-determination—were not part of our vocabulary in June 1971. We've come a long way in 25 years!

Spring 1969

Psy-Ed Corporation is founded by three clinical psychologists, Lewis B. Klebanoff, Stanley D. Klein and Maxwell J. Schleifer, to provide information for parents of children and young adults with disabilities.

> *We knew that a great deal of information presented to parents was often presented in an incomprehensible and impractical way. We also knew parents were capable experts about their own children, not the troubled, anxious people perceived by many professionals.*
>
> *—S.D.K.*

1970

A sample newsletter, entitled *The Exceptional Parent*, is distributed to colleagues. Publishing a magazine is suggested.

> *In our efforts to find financial backing, we met with people in the publishing industry. The opinion of these experts was unanimous. They thought we were "out of our minds" to try to do something like this as a private venture because we would never be able to raise enough money to do it successfully. Looking back, it was fortunate that we didn't understand what people were telling us. We denied their unanimous assessment of our mental state, and went on with our plans using borrowed funds.*
>
> *—S.D.K.*

June 1971

The first issue (June/July) is published with 32 pages and no advertising. The issue includes an interview with several parents, an article by an adult with a disability who typed with a mouth stick, and an editorial urging use of the term "disability" rather than "handicap."

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A review appears in *Time* magazine, praising EXCEPTIONAL PARENT for its "bold and touching goal: to alter the temper of the nation by influencing normal as well as abnormal children."

August/September 1971

An editorial urges professionals to stop blaming parents:

...With many disabilities, it is clear at birth that life for both family and infant will be difficult. Often the hospital staff does not clearly explain to the family what they are likely to encounter. Nor do they make it clear why it will be necessary for them to initiate and maintain contact with a variety of specialists... Until society makes sure that there are adequate assessments and services for all babies and their parents, the problems of early diagnosis and appropriate intervention will persist.

...parents are encouraged to accept, not only the assumption that the reason for a lack of educational opportunities lies in the child's disability, but also that their desire to have the child included in public school is part of the child's problem. Once again, they are asked to assume blame for their own activities.

...[Parents and professionals] trapped in this fruitless and, often painful, mutual encounter... unnecessarily expend a great deal of energy... criticizing each other. Until they join forces they will be limited in providing new and better opportunities.

...Society has implicitly blamed and punished those parents and professionals who have attempted to shout about their pain and anguish. And finally, professionals and families have often, unwittingly, accepted society's limited investment in them.

We do not believe that the parents or the professionals should stop their search for better ways of helping the disabled child... We do believe that without dreams of the ideal, they may wander aimlessly, searching for new directions.

In the same issue, Editorial Advisory Board member and Massachusetts legislator Michael S. Dukakis urges parent involvement to help "exceptional children realize their full potential as human beings and as citizens."

October/November 1971

The magazine writes open letters to several television producers supporting the participation of children with disabilities in children's television programming. The "Parent Power" editorial encourages parent groups to "join together to have power."

...We live in a society of jockeying power groups. There is nothing evil about that, but it does require that we learn to use power to accomplish our goals. As we do, we will hasten the day when continuing, comprehensive community services are available to all children with disabilities... That's not a bad use of power, is it?

When the magazine first began, we felt that some of our readers would not want the postman or others to know that they had a child with a disability, so our first few issues were mailed out in a brown paper wrapper. Eventually, we abandoned the wrapper because we realized that covering up the magazine had more to do with our own discomfort.

—S.D.K.

December 1971/January 1972

The magazine reports on a landmark judicial decision in Pennsylvania, which affirmed educational rights for children with mental retardation.

...the diagnosis of mental retardation cannot be used as a reason for excluding a child from educational programs... every retarded person between the ages of 6 and 21 years must have access to a free public program of education and training appropriate to his learning capacities...

June/July 1972

The editors urge Democratic and Republican platform committees to address specific questions regarding the needs of children with disabilities and their families. The first part of an interview with four siblings of children with disabilities is published. The words of one participant illustrate how rarely this topic was discussed within families: "I wonder what the hell is going to come out because I really have not discussed this with anyone."

August/September 1972

National political parties respond to our questions. Statements by Senator Robert Dole, Chairman of the Republican National Committee, and by "Handicapped Citizens for McGovern" are published.

continued on page 102

We owe an enormous debt to Stan Klein and Max Schleifer. They conceived of this magazine 25 years ago, and they brought it to fruition. Meanwhile, Stan and his colleagues have fought to maintain it through thick and thin—and there surely have been some thin times. Their dedication to the service they offer a vulnerable sector of our society has impressed me deeply over the years.

How many families and children with special needs have profited by their effort! The parents of special needs children I have known over the years have looked to EXCEPTIONAL PARENT to find solace. They have experienced a sense of community and of sharing with others that has mitigated their pain. They have found invaluable suggestions for interventions to optimize their child's development. I feel such a debt of gratitude that the magazine has been able to address these issues so openly and supportively for a too often neglected sector of our society. Here's to 25 more!

—T. Berry Brazelton, M.D.
Clinical Professor Emeritus of Pediatrics
Harvard Medical School

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Circle #54

continued from page 101

Every four years since, we have published thoughtful statements from both the Democratic and Republican candidates for President of the United States. These have contributed to increased awareness on the part of candidates and greater advocacy efforts by parents and caring professionals.

—S.D.K.

November 1972

A very thin October/November/ December issue is published. The financial situation of the magazine is precarious; money and credit are running out.

February 1973

Readers are informed that the January/ February issue will not be published.

March 1973

Ann Landers praises EXCEPTIONAL PARENT in her syndicated column, producing more than 10,000 inquiries about the magazine.

As a result of Ann Landers' mention of EXCEPTIONAL PARENT, a New York publishing company agreed to acquire our company in return for financing the magazine for one year.

Since 1973, Ann Landers has written about EXCEPTIONAL PARENT magazine eight times. While we managed to limp through 1974 without her, we probably would have gone under in 1975 without her second intervention. To us, Ann Landers has been a super-heroine, who has rescued us from impending disaster at least twice. We are very grateful to her.

—S.D.K.

May 1973

The March/April issue is published under the auspices of the New York publisher. The sale of advertising begins.

Before this time, the magazine did not contain advertising. As clinicians and educators, we were concerned that readers would perceive advertising in EXCEPTIONAL PARENT as an endorsement of the product or service. But late in 1972, an executive in the magazine industry single-handedly changed our minds.

Reminding us of our own editorial writings, this parent said that if we truly believed that parents were intelligent consumers, we should accept reputable advertising. He told us that in searching for information about wheelchairs for his son, he had subscribed to overseas publications because adequate information was not available in the United States. He pointed out that advertising was a service to him. As a consumer, he wanted information to help him make choices; he did not perceive the presence of an ad in our magazine as an endorsement.

—S.D.K.

May/June 1973

The issue includes the first part of an interview with four young adults with disabilities and an article by a parent advocating for her right to read confidential professional

Congratulations to EXCEPTIONAL PARENT for 25 years of exceptional focus on a subject too long ignored. Long may you reign.

—Ann Landers
Syndicated columnist

records about her child. Also, we print the first report on Senate Bill 6, the Education for All Handicapped Children Act:

It is the purpose of this Act to insure that all handicapped children have available to them not later than 1976 a free appropriate education.

...The education that this bill can make possible is going to cost money... this expense is minimal compared to what it has cost this society to deny appropriate services and maintain handicapped children at a level which is far less than their potential... all children have the right to an education which meets their needs.

September/October 1978

Lisa Blumberg, a senior at Wellesley College, presents "The Case for Integrated Schooling." Ms. Blumberg, who has cerebral palsy, went on to graduate from Harvard Law School; she is now a practicing attorney. In the years following her first appearance in these pages, she published other important articles and became a member of our Editorial Advisory Board.

Through six years in public schools, private schools in two different locations and college, I have had good times and bad times, but I have always been glad that I have been in regular schools. I feel that I benefited academically, emotionally and socially from having gone to regular schools rather than to special ones.

...Because disabled children are individuals with individual needs, it is ridiculous to think that there is one universally correct decision. There are, no doubt, some physically or sensorially disabled children for whom special schools may indeed be the best answer. However, I think that too often children who should be in regular schools and would do well there are sent to special schools for reasons that are ill-founded or unjustified.

...Exposing nondisabled children to children with physical or sensory disabilities can only make them more accepting of all kinds of people. It will provide them with living proof that people with limitations in some areas do have talents and abilities. I think that prejudice against the disabled will only begin to be eliminated when significant numbers of disabled children go to school side by side with nondisabled children.

continued on page 104

Sandy L.
Chicago Artist
C-6 quadriplegic

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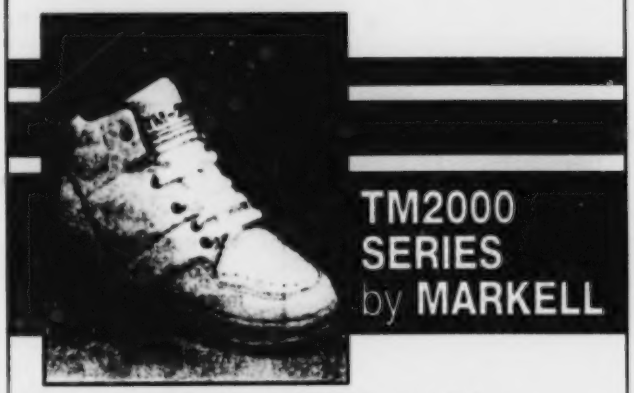

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Circle #48

584

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Circle #56

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- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle #30

The National Parent Network on Disabilities (NPND) applauds the success of EXCEPTIONAL PARENT during 25 years of fantastic help for parents.

NPND entered into a partnership with EXCEPTIONAL PARENT five years ago, a partnership that we feel is invaluable. EXCEPTIONAL PARENT is extremely helpful to parents, not only in the factual information it provides, but in the shared advice, resources and contacts parents can access through its pages. Not to be overlooked is the confidence parents can gain in parenting a child or young adult with a disability as they read about the similar experiences of other families.

Best wishes for your continued success.

—Patricia McGill Smith, Executive Director
National Parent Network on Disabilities

Patty Smith (left) and daughter Jane, 27, show off a check from MetLife to the National Parent Network on Disabilities to fund programs for children.

continued from page 104

By this time, the New York publishing company realized they were losing money on EXCEPTIONAL PARENT. The magazine was returned to us after the January/February 1974 issue.

—S.D.K.

March/April 1971

In an editorial entitled "Disappearing in the Community," we reported on concerns still relevant today:

We are observing and participating in dramatic reorderings of the lives of disabled children and adults. First, large institutions are changing and some of the human beings who have been confined within them are being placed in smaller community-based settings. Second, throughout the country, children with disabilities are being integrated into regular classes in public schools.

...Amidst the excitement and enthusiasm accompanying these dramatic changes there have been some troubling reports. Some big, inhumane institutions are being replaced by small, inhumane mini-institutions. Some children with disabilities are sitting in regular classrooms but are without educational programs that meet their needs.

...Thus, in some communities, public education efforts have been amazingly successful yet woefully incomplete. That is, the public and its governments have become convinced that many public institutions (and special classes) are not good places for human beings to live or to grow. However, the public and its governments have sometimes acted as if the mere placement of individuals in a "wonderful" real world (community) setting will be the solution. It is as if the institution or the educational segregation process caused the disability, and therefore, by removing

585

the bad institution or the bad segregated educational setting, the human being's disability (and his needs for special help) will disappear.

January/February 1975

After we run an article on respite care, author Ruth Case and her colleagues receive more than 1,000 letters from around the world.

Parents of children with disabilities are all too familiar with the problem of finding overnight or short-term care. Such care may be needed for many reasons: to enable a family to take a vacation, cope with an emergency or find relief (respite) from the heavy demands of constant care of someone with special needs... There has been a serious need for an alternative for these families and children which would closely approximate the warmth, familiarity and atmosphere of their own home.

...The respite program is a community-based, family-centered alternative to institutional care. Temporary care (not more than thirty days) and loving attention for a disabled child is provided in the home of another family—a "respite family."

In the same issue, we publish "Stop Worrying? Nonsense!" by VaDonna Jean Leaf, again supporting the expertise of parents.

...we're all pioneers. How many of us knew anything at all about disability before we were confronted with the condition in our child? How much have we learned since then? A great deal.

...it is we, the parents, who have the abiding responsibility for our child throughout his dependent life, whether for a few years or well into his adulthood. Often, this ongoing support and effort by parents is what makes the difference between whether a child ultimately "makes it" as an adult or not. The professional's help, though vital at each point, is transitory. No matter how well- or poorly-equipped we are to meet the ongoing demands, we bear the responsibility for orchestrating the help our child needs—and the care our child gets.

What about the advice to "Stop worrying!"? That is about the most outlandish combination of words that I can think of... As long as a problem remains unresolved, one for which we feel responsibility, it's human nature to be in a state of active concern. And when the problem involves our own child who has special difficulties, we worry.

...The message in all this is "Trust yourself!" Because of your close bond with your children, because you have been alerted by your concern to act on their behalf, because you know them "subjectively," you do a job for your children that no one else can do. Fellow parents, you're okay!

December 1975

President Gerald Ford signs S. 6, the Education for All Handicapped Children Act of 1975, and a new era begins. However, President Ford also shared his concerns—concerns that continue to this day:

...this bill promises more than the Federal Government can deliver and its good intentions could be thwarted... Everyone can agree with the objective: educating all handicapped children in our nation...

...the funding levels proposed in this bill will simply not be possible if Federal expenditures are to be brought under control and a balanced budget achieved.

continued on page 106

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Circle #64

continued from page 105

The Education for All Handicapped Children Act of 1975 mandated individualized educational plans (IEPs), education for children in the least restrictive environment, parent/professional collaboration and much more. Parents and professionals have written many fine articles on these topics as new programs evolved. Most of all, we learned that many children with disabilities were far more capable than we had expected.

—S.D.K.

June 1976

"Parent to Parent Support" shows how "experienced" parents reach out to new parents of children with disabilities. The parent-to-parent movement grew to serve thousands of parents in the next 20 years.

When the magazine first began, we did not use many pictures of children with disabilities. Our advertisers tended to present products without actually showing people with disabilities using them. Soon, we invited parents to send in pictures of their children and themselves. We also encouraged our advertisers to show real children using real equipment or participating in real educational programs.

—S.D.K.

April 1978

An article by Stanford J. Searl, Jr., father of a daughter with mental retardation, questions the concept of parental stages of reaction to the diagnosis of a disability in a child.

...Professionals could help parents more—and they would be more realistic—if they discarded their ideas about stages and progress. They could then begin to understand something about the deep, lasting changes that life with a retarded son or daughter brings to parents. And they could begin to see that the negative feelings—the shock, the guilt and the bitterness—never disappear but stay on as a part of the parents' emotional life.

August 1978

As children with disabilities began to be more visible in public schools, we discuss the need to educate all children about their newly arrived peers. In "Mainstreaming: What Every Child Needs to Know About Disabilities," Susan Bookbinder writes about this topic.

...Mainstreaming will be successful only if teachers and other public school staff are fully and knowledgeably committed to meeting the special needs of the disabled children who will be joining their classes. Even more important, understanding and acceptance are required from the other children.

...Many disabled children grow up unnecessarily handicapped by the reactions of the people around them to their disability. The confusion, or diffidence, or hostility of others all too quickly may

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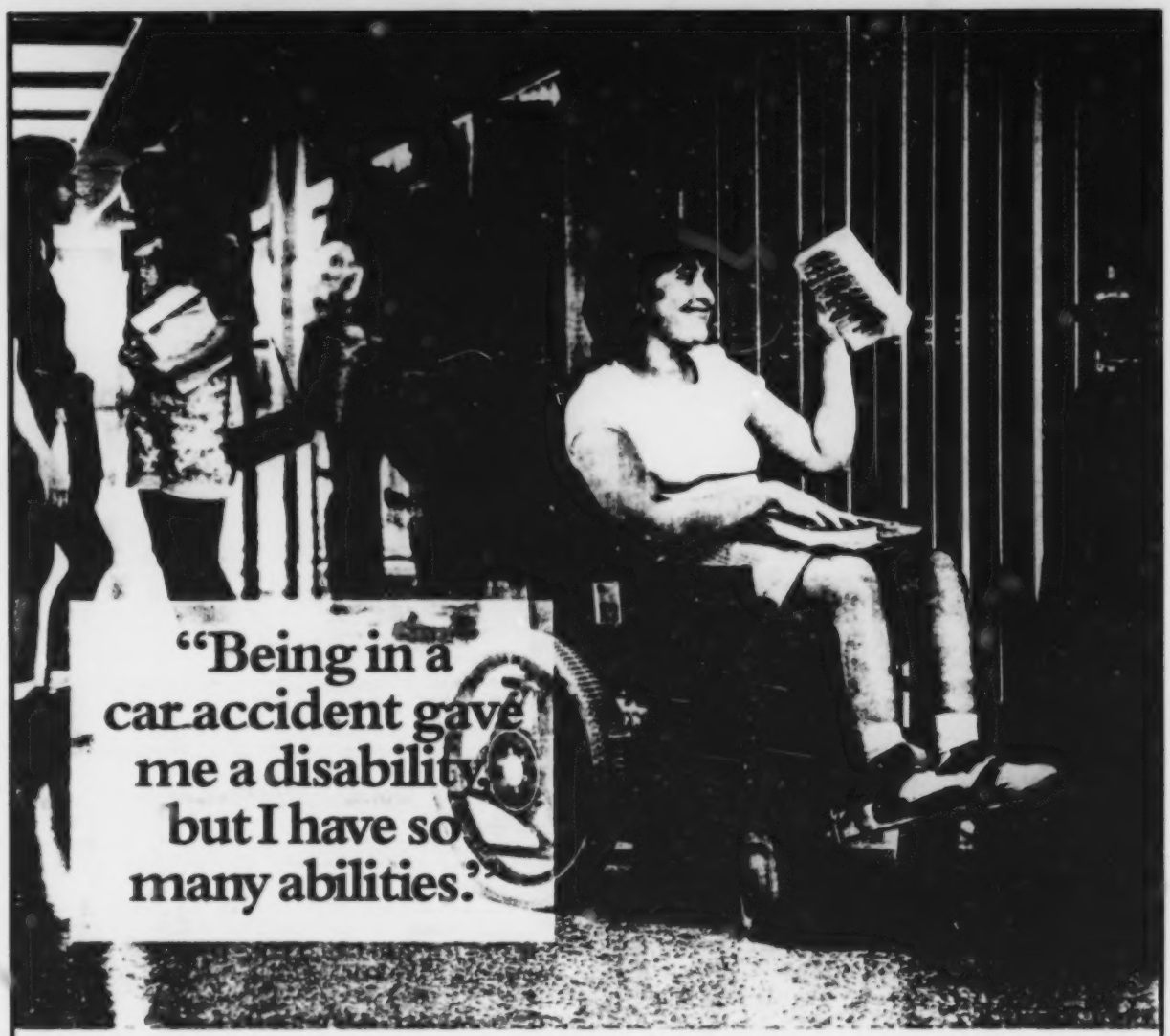

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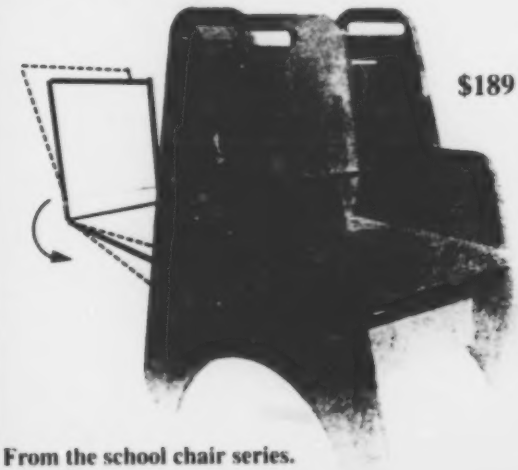

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Circle #31

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convince children with disabilities that their differences set them irrevocably apart. Disabled children need to know, and to experience, that they can be accepted by their peers; they need to believe that they, too, can learn, and to have others recognize that they can.

December 1979

We publish a powerful article, "Grieving and Sharing," by Sherry Golden:

It all begins the moment someone, usually a medical specialist, tells you your child is not and never will be normal. Looking back, this is the moment in which your life and the life of your family changes in crucial, irrevocable ways. Threads and themes of your life continue on and yet you are never quite the same as you were before.

...The experience of being told about a child's disabilities has a brutal, assaultive quality. Words become blows; it feels like a kind of dying where breathing halts, senses numb and the life seems to drain out of you. Images of your proud self among an approving community of family and friends seem swallowed up by a shadowy world of arcane specialists and fearfully afflicted people.

...The hopes and dreams and fears you have spun for yourself and your family throughout pregnancy, the roles and expectations you have been taught and imagined, the images of a child who will grow uniquely, but in a familiar mode—all, for the moment at least, are rendered meaningless.

It is a moment of immense helplessness and great pain. It is also a unique crossroads of life and birth, death and loss which brings to bear the social and personal meanings of each...

October 1980

We present the views of Presidential candidate Ronald Reagan:

The implementation of Public Law 94-142 was perhaps the greatest stride made to date toward a workable plan for the education of handicapped children. As President, I will work to ensure that the Education for All Handicapped Children Act is a success. But P.L. 94-142 needs clarification and revision if it is to be truly successful in helping every exceptional child overcome the barriers placed in front of him by his handicap.

June 1981

EXCEPTIONAL PARENT celebrates its 10th Anniversary!

By our 10th anniversary issue in 1981, we had become pretty well established. We had received acclaim from a wide range of organizations and individuals. Although our subscription marketing efforts continued to be hampered by limited resources, we did reasonably well through word-of-mouth and pass-along subscriptions and our renewals. We added a few more staff members, and the drain on our personal energy as well as our pocketbooks decreased.

—S.D.K.

December 1981

In this issue, Harilyn Rousso, a psychotherapist, who would later become a member of our Editorial Advisory Board, writes about sexuality:

...Although people are often afraid of directly discussing sexuality, open communication and knowledge are never really the enemy. In my view, the real enemy is the conspiracy of silence around sexuality, and particularly around sexuality and disability, which only supports myths, distortions and confusion. Disabled children and adults pay a high price for this silence.

One of my most amazing discoveries when I first started going out was that it was not so hard, that there was nothing out there that was beyond me. I could be accepted, appreciated, even desired—disability and all—not by all people, but by enough people. While this discovery was a source of great joy, it also made me sad and angry because I had missed out unnecessarily on a great deal of time and opportunities for socializing, for social and sexual expression. I say unnecessarily because it was only a myth, the myth of asexuality, of lack of sexual entitlement, which held me back.

February 1982

President Reagan's comments in EXCEPTIONAL PARENT as a candidate were noted by Congress—285 members cite those published comments in a letter to the President:

We are writing to request your assistance in assuring continued support for P.L. 94-142, the Education for All Handicapped Children Act, and its support programs.

...We hope that you will reaffirm your pledge by endorsing current levels of federal funding for P.L. 94-142 and its support programs, and opposing any substantive changes in the statute.

June 1983

For the first time, we feature articles about computers and technological advances made for people with disabilities. We also report on "the coming of age of parent power" with an article on The National Network on Parent Coalitions which had begun in 1982. In future years, it would become the National Parent Network on Disabilities (NPND), a major voice for parents.

August 1983

We publish our first resource directory listing 120 organizations and agencies. Little did we know that in 1996, our January Resource Guide would list more than 1,000!

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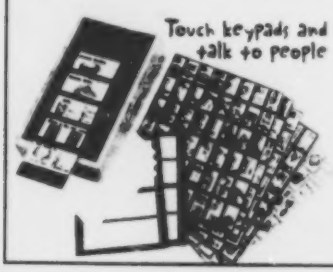

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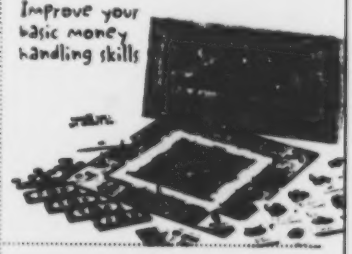

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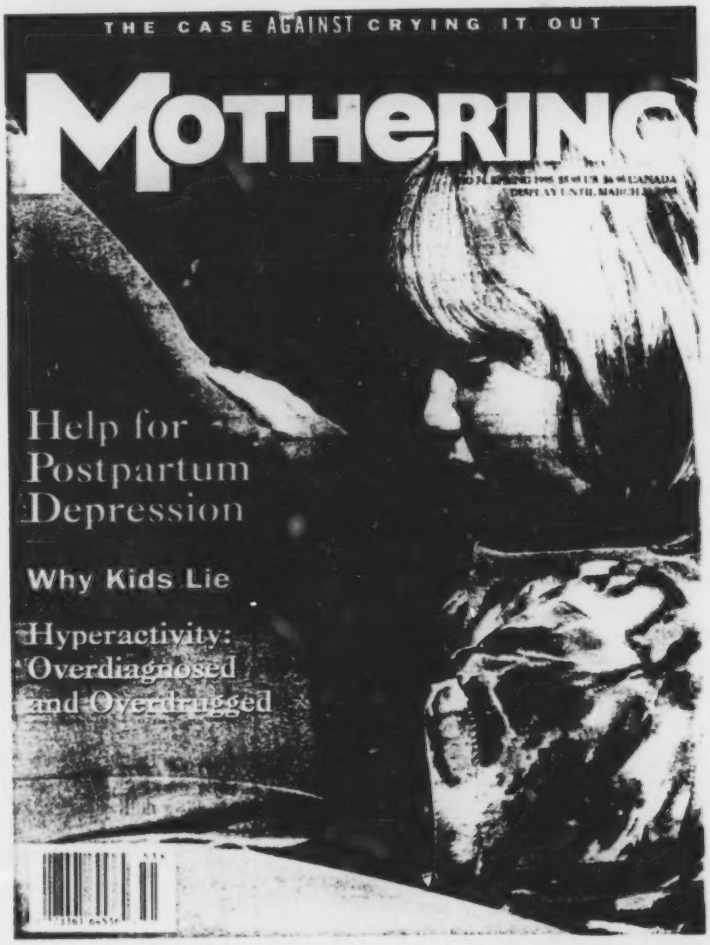

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Circle #110

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February 1981

We begin to publish eight issues each year. In this issue, we run a powerful piece about parental grieving by Audrey T. McCollum.

...When a child's health is impaired, parents can be confronted harshly and abruptly with a reality that allows little or no hope for fulfillment of their dreams. A child with muscular dystrophy is not likely to become a pro football player; a child with Down syndrome is not likely to win a Nobel Prize.

So the fantasied child is lost and a process of grieving begins. Of course, most parents do feel genuine sorrow for the child whose health is impaired. But...parents grieve for themselves in their state of loss.

...Grief is intensely painful. But psychological distress that is experienced and mastered results in the growth necessary to deal effectively with life's adversities and also to experience its joys. The lost dream can be transformed into a new vision.

August 1981

We print the U.S. Supreme Court decision in *Irving Independent School District v. Tatro*, which upholds the Education for All Handicapped Children Act and affirms support for services a child might need in order to attend school—all because Mary Tatro, a courageous mother in Texas, knew that her daughter could participate in regular classes. We also publish our first Children's Pages:

I have a learning disability, and that's okay because I know pretty much how to cope with it.

...Some people think it's weird—the word "disability." I have tried to explain to my friends what it is. Then once I do, I can tell by the look on their faces that they don't understand.

...I feel sorry for those people because they can't accept other people with different problems. I can though, because I am a survivor!

–Ruth Anderson

July 1985

We publish several editorials on "Keeping the Care in Health Care," a topic still in the forefront today.

...We are concerned that the relentless drive toward lower costs and greater efficiency will leave an important question unanswered: How will changes in health care services and delivery systems affect children and adults with disabilities?

We insist that health care not be treated purely as an "industry." Managing human care like an automobile repair business—with standardized diagnoses and spare parts—ignores the diversity of people's lives and needs. "Off-the-rack" health care, we fear, may be especially detrimental to children and adults with disabilities.

October 1985

Jacquelyn Brand reports on The Disabled Children's Computer Group of El Cerrito, California, which provides

continued on page 112

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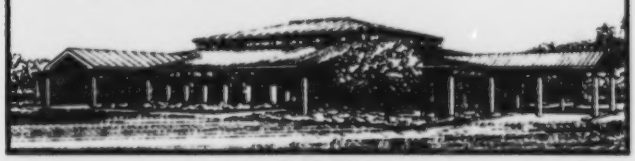

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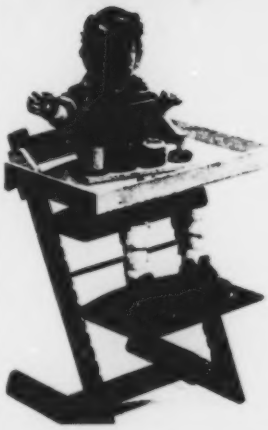

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Circle #35

Judith Heumann (left) spends some time with friends Christopher Levintow, 5 months, and Ann Cupelo.

Since the enactment of the Individuals with Disabilities Education Act (IDEA) more than 20 years ago, we in the disability and special education communities have seen time and time again the crucial role that parents and families must play in achieving successful results for their children with disabilities. Indeed, family involvement in the educational process is of such great importance that it serves as one of the cornerstones upon which the Clinton Administration's IDEA reauthorization proposal is based. The promotion of parent and family involvement is also one of Secretary of Education Richard Riley's major initiatives for improving educational outcomes for all children.

Through its efforts to bring parents and professionals together, and provide families with the critical information they need to take an active part in shaping educational services and outcomes for their children, EXCEPTIONAL PARENT magazine meets a critical need in the special education arena. May your next 25 years be as exciting and productive as your first. Happy Anniversary, EXCEPTIONAL PARENT!

—Judith E. Heumann
Assistant Secretary for Special Education and Rehabilitative Services, U.S. Department of Education

continued from page 111

hands-on computer experience for children with disabilities.

The Disabled Children's Computer Group and Apple Computer joined together to create the Alliance for Technology Access (ATA) in 1987. The ATA has since grown into a major resource to help adults and children gain access to the benefits of adaptive technology.

—S.D.K.

December 1985

The issue features several articles on life as an adult with a disability: finding a job, choosing a living option and exploring sexuality. "Owning Our Own Home: A New Model for Independent Living" by David and Margot Wizansky highlights a new housing program:

...we have facilitated the development of 22 units of condominium housing for adults with developmental disabilities in Brookline, Massachusetts. This was a joint venture of parents and residents with considerable help from an architect/developer and an attorney.

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…These "chaperoned" condominium boarding houses combine the opportunity for residents (and parents) to own their own homes while enjoying the friendship and support of other unit owners and around-the-clock trained staff.

April 1986

We dedicate the issue to teenagers with disabilities and the topics concerning them: getting a driver's license, taking the SATs, finding positive role models and even the controversial topic of sterilization.

November 1986

We report on early intervention and new amendments to the Education for All Handicapped Children Act. And, although we had always facilitated the exchange of letters and information between readers through our *Readers' Forum* department—initiated in the first issue of the magazine 15 years earlier—we formalize this process with the introduction of a new department, *Readers Search*, which evolved into what is now known as *Search & Respond*.

> *We encouraged parents to send in questions with the hope that other parents and readers would respond. At first, we were fearful about what people might share with one another. But we overcame that fear by going back to our basic assumption about parents—that they are the real experts.*
>
> —*S.D.K.*

March 1987

In addition to articles on recreation and leisure, the March issue features a powerful letter by Paul Pendler, written to his mother on the night before his sister with Down syndrome moves into a group residence:

I have experienced a special kind of life having a disabled sister, and in many ways, a more enriched life. I hope that once I start working with retarded people and their families, I can help them to understand the importance of being open with their feelings. I also hope I can use my career to open group residences that will allow all the qualities Lisa has to flourish and flow to others like herself. She is very wonderful in her own special way—just as we all are—in our own special ways.

May/June 1989

More than 2,800 readers respond to a survey about respite care that appeared in the October 1988 issue.

October 1989

We feature an editorial praising *Life Goes On*, a new ABC-TV television series featuring Christopher Burke, an actor with Down syndrome, as "Corky."

ABC-TV has taken a giant step forward in helping us all see people with disabilities more clearly–without myths and prejudices nor bitter exclusion or

continued on page 117

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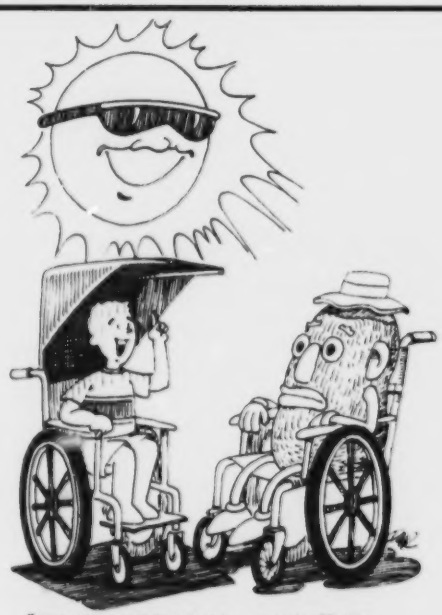

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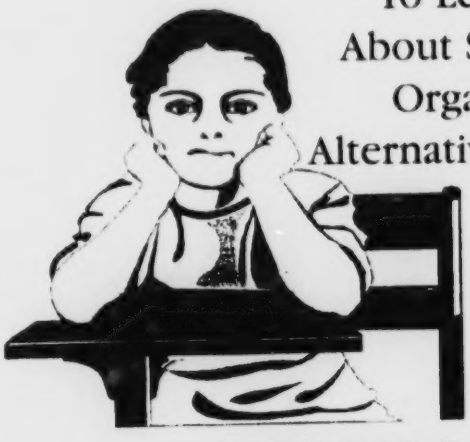

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maudlin sentimentality... Corky is a real person. His personality is shaped by the family and community. As a person, Corky has the diligence to pursue interests that he wishes to master along with a wide range of human feelings and desires—just like the other teenagers in his community.

March 1990

We publish a special insert, *The 1990 Wheelchair Guide*, featuring various mobility options for children, to help parents make better product choices. This was the first of what became our annual mobility issue.

September 1990

Fifteen years after the signing of the Education for All Handicapped Children Act, the Americans with Disabilities Act is signed by President George Bush. At the ceremony, Senator Tom Harkin (D–Iowa) says, "With the passage of ADA, we as a society make a pledge that every child with a disability will have the opportunity to maximize his or her potential to live proud, productive and prosperous lives in the mainstream of our society."

April/May 1991

The theme of the issue is "Fathers Speak Out," featuring two very powerful articles written by fathers of children with disabilities. Richard C. Anderson writes:

I have thought about how Walter's autism affects my love for him; I mean, would I feel differently if he were "normal"? I do not know a Walter who is "normal." That would be a different person. I know and love the Walter who has autism... Of course, I wish he did not have disabilities, and I want him to develop to his maximum potential, but I do not wish he were different.

October 1991

Amendments to the Education for all Handicapped Children Act strengthens the law and change its name to the Individuals with Disabilities Education Act (IDEA).

April/May 1992

Through articles, we meet James May of The National Fathers' Network, now the coordinator for our regular department, *Fathers' Voices*.

July/August 1993

EXCEPTIONAL PARENT experiences many changes: co-founder Maxwell J. Schleifer steps down from his key role as editor-in-chief; Joseph M. Valenzano, Jr., an experienced publishing executive and a parent, becomes president of a

continued on page 118

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continued from page 117

newly reorganized Psy-Ed Corporation and publisher of EXCEPTIONAL PARENT; and the magazine's publishing office opens in Hackensack, New Jersey, while the editorial office remains in Brookline, Massachusetts.

September 1993

Our annual education issue reports on inclusion programs illustrating the shift from mainstreaming to inclusion. After serving on the psychology faculty at Gallaudet University, Kim Schive joins our editorial staff, bringing her expertise as a person with a disability and as an adoptive parent of a child with a disability.

October 1993

Fathers' Voices becomes a regular department, beginning with "Images of Fathers" by James May:

...so many men... are afraid to share their special world, fearful of being misunderstood and often unwilling to reach out to others for help. So many still believe that a man is supposed to take charge, be self-sufficient and handle all his problems without asking for help. The old male stereotypes die hard. To finally be able to talk openly about one's child is an incredibly powerful experience. When we talk to each other we realize that we all have the same fears, angers, frustrations and joys. Isolation slips away.

January 1994

EXCEPTIONAL PARENT becomes a monthly publication and gets a new, improved look!

February 1994

Role Models becomes a regular department, beginning with Judy Heumann, Assistant Secretary of Education for Special Education and Rehabilitative Services.

I think that sometimes parents of disabled children think that it's better for their kids not to be around other disabled kids because they want to help them become more integrated. I think that attitude is a big mistake. I think we need to look at disabled children and adults like other minority groups. I think we need to recognize that being different isn't necessarily negative.

July 1994

Ask the Doctor by David Hirsch, M.D., and *Health Insurance Troubleshooter* by Richard Epstein become regular question-and-answer departments.

December 1994

Our issue devoted to "Religious Participation for All" wins widespread praise for articles such as "Catholic Life for

Children with Disabilities," "A Jewish Education for Every Child" and "Toward a More Inclusive Protestant Sunday School." Rev. Bill Gaventa writes:

Today... many parents, professionals and religious leaders realize that religious education and congregational life offers unique and wonderful opportunities for children with disabilities. Besides giving children an opportunity to learn and grow in their faith tradition, participation in congregational life may allow them to realize that they, too, are part of God's people with gifts to be celebrated and needs to be shared.

August 1995

In "A New Twist to 'Playing Doctor'" by Rick Rader, we learn how teenagers and young adults with disabilities serve as patient simulators and help teach medical students how to care for people with disabilities.

January 1996

Our 25th Anniversary year begins with the most extensive Annual Resource Guide ever—including more than 1,000 organizations and agencies and extensive cross-referencing of specific disability groups.

> *It has never been an easy task for us to learn to write for human consumption, rather than for professional consumption. But of all the things we have accomplished, I think this is one of the most important. We continue to ask ourselves about every article: Does this make any sense; and will the reader, who may be isolated from services or an undereducated individual, be able to understand and apply the material in a practical way to his or her day-to-day life? These continue to be our criteria for everything we publish.*
>
> —S.D.K.

Looking to the future

We have been very lucky. Most of all, we have had wonderful support from our families and friends, as well as from our fine staff. Many people in the publishing industry, in the organizations that serve families and in professional fields have also been very helpful to us. To all of them, we offer a heartfelt thank you.

Our challenge for the rest of the 1990's and the next century is to make sure that the promise of the Americans with Disabilities Act becomes a reality for everyone with a disability—children, adults and senior citizens.

As for the magazine itself, we hope to see it translated into other languages, so that parents can participate in a caring network throughout the world, benefiting from the know-how and experiences of other parents and people with disabilities, wherever they may live.

We look forward to the next 25 years and, in the more immediate future, to joining our readers and their family members at our special 25th Anniversary celebration and conference, "EXCEPTIONAL PARENT Live," in Anaheim, California, October 17–20, 1996. **EP**

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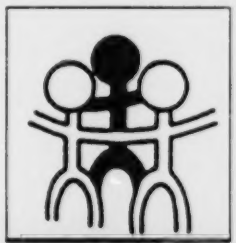

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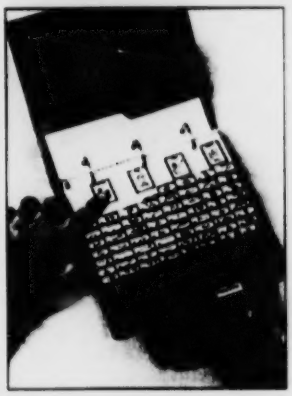

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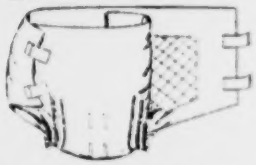

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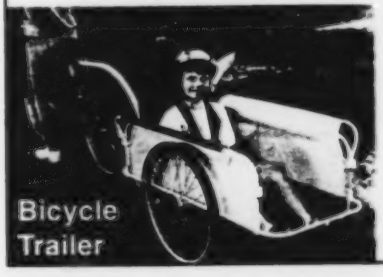

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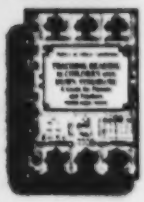

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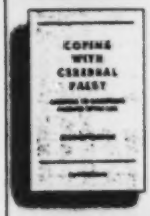

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C.T. DIGLI, M.D. & S.L. KINMAN, M.D.
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The 3R's For Parents, Rights, Resources, and Results
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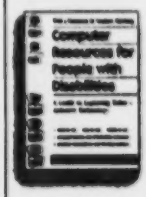

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J. THORNBURGH
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**Ask about special bulk rates for this series.*

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Sub-Total
Shipping
TOTAL

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Account Number _____ Exp. Date ____
Signature _____

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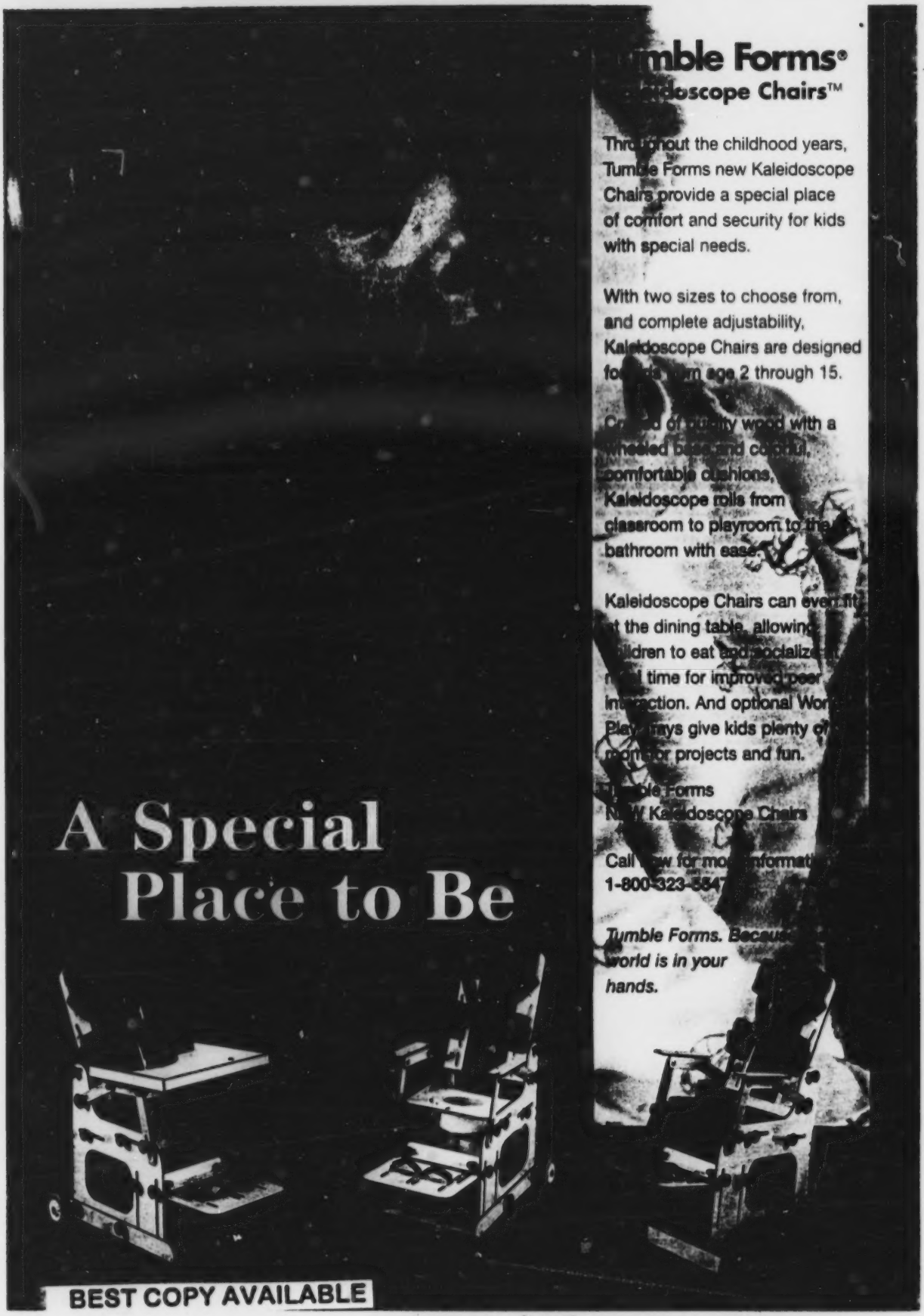
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Call now for more information
1-800-323-5547
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A Special Place to Be

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JULY 1996

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EX

Parenting Your Child or Young Adult With A Disability

25th Anniversary
1971-1996

Juggling Family & Career

When Children Die

Family-Centered Care Lowers Stress

Directory of Vans & Van Conversion Dealers

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Ford Motor Company understands that a physical disability doesn't mean life can't be rewarding. For many, there's no greater reward than the feeling of freedom and independence that comes from driving.

That's why your Ford and Lincoln-Mercury dealers are ready to help your active life include a new 1995 or 1996 Ford or Lincoln-Mercury vehicle. The Mobility Motoring Program was created to make adapting your new vehicle easier and more rewarding!

A SMOOTHER ROAD TO TRAVEL

Mobility Motoring starts with a toll-free call and concludes when your Ford or Lincoln-Mercury dealer hands you a check for up to $750 toward the installation of adaptive driving or passenger equipment. There's nothing for you to send in, and there's no waiting for your check!

You'll also receive a complimentary Ford Cellular Telephone[1] and Roadside Assistance[2] for the duration of the bumper-to-bumper limited warranty.

INFORMATION YOU NEED FOR INFORMED DECISIONS

The Ford Mobility Motoring Program also provides ...

- a list of nearby assessment centers authorized to provide a "prescription" for your vehicle's adaptive equipment.
- a list of local adaptive equipment dealers and installers.
- a video that shows adapted Ford and Lincoln-Mercury vehicles, and introduces you to people who are experiencing the independence of driving.

Ford
MOBILITY MOTORING PROGRAM

- sources of funding which may be able to provide assistance *in addition* to the amount you receive from the Mobility Motoring Program.

PROGRAM PERIOD

October 1, 1995 – September 30, 1996

When you're ready to adapt a new Ford or Lincoln-Mercury vehicle just call **1-800-952-2248** (for TDD users, **1-800-TDD-0312**). You'll discover that Mobility Motoring is your kind of reward!

[1] Customer is responsible for a 121 day minimum new activation on the Ford Cellular System. Some local individual carriers may require a longer agreement as well as other related service and usage charges, so acceptance is optional. To be eligible for the complimentary Ford Cellular Telephone, the customer must also live in an area covered by the Ford Cellular System at the time of the purchase or lease.

[2] Ask your dealer for a copy of the limited warranty and complete details of the Roadside Assistance Plan. Vehicles covered by the Lincoln Commitment, Mercury Commitment or Red Carpet Lease plans may have additional benefits.

Circle #24

A NEW FORD OR LINCOLN-MERCURY VEHICLE ... ADAPTIVE EQUIPMENT ... AND ON-THE-SPOT-CASH!

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EXCEPTIONAL PARENT
PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY
Since 1971
The Magazine for Families and Professionals

PUBLISHER'S LETTER

July 1996

The First Exhibition of the 21st Century!

Dear Reader:

This issue of *Exceptional Parent* includes some very exciting news, for us and for you. On pages 43 through 46, we announce our first-ever *Exceptional Parent* Conference & Exhibition.

It's **Forum '96: *Exceptional Parent* Live, A 25th Anniversary Celebration!** It will be held October 17-20, 1996, in the Anaheim Hilton Hotel ... and it will be a national conference of parents and leading professionals ... of teaching-and-learning seminars and workshops on today's most important family-oriented topics ... of informational exhibits and of networking opportunities for parents and professionals ... of state-of-the-art interactive exhibits and activities ... and of just plain fun for kids and their families.

It all happens in less than four short months. There has never been anything like it (after seeing the plans, one marketer called Forum '96 "the first Exhibition of the 21st century"), and it's not too soon to start making your plans to attend.

I urge you (and your whole family!) to read all about Forum '96, starting on page 43 and, if at all possible, to attend ... to participate, learn and network ... and to enjoy four wonderful days of family fun and excitement in California, within walking distance of Disneyland.

See you in Anaheim!

Cordially,

Joseph M. Valenzano, Jr.
President & Publisher

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EXCEPTIONAL PARENT

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

Since1971

The Magazine for Families and Professionals

JULY 1996 VOL. 26, ISSUE 7

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Cover: This boy enjoyed a Disney World vacation with his family thanks to Give Kids The World, a non-profit organization that provides central Florida vacations for families of children with life-threatening illnesses.

Henri Landwirth (pictured above), a 69-year-old Holocaust survivor, created Give Kids The World in 1986, initially running the organization from his Holiday Inn in Kissimmee, Florida. In 1989, he opened Give Kids The World Village, which features 56 specially designed villas, a swimming pool, playground, nature trail, ice-cream parlor, chapel and a 4,000-square-wfoot game room and fun house. Give Kids The World Village has hosted over 25,000 families from more than 40 countries.

Contact Give Kids The World, 210 South Bass Rd., Kissimmee, FL 34746; (407) 396-1114 (voice); (407) 396-1207 (fax).

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EDITOR'S DESK

Juggling family and career

This may be the latest hot topic in the media and among politicians, but it is not a new challenge for most parents. And parents of children with disabilities have always faced special challenges in finding the time and energy to meet the needs of everyone in the family.

In the 1960s and 1970s, when a young child was diagnosed with a disability, well-intended professionals often recommended placing the child in a public institution. There were at least two interrelated reasons for this recommendation. First was the concern that parents—especially mothers—would not have enough time and energy to raise a child with a disability along with other children. Second was the lack of services in most communities. Programs like early intervention services or respite care did not exist. School-age children were often excluded from public schools or placed in partial-day special education programs that were often woefully inadequate. This lack of services meant that someone needed to care for the child around the clock, with no vacations.

STANLEY D. KLEIN, PH.D.

The services and legislation that began to evolve in the 1960s and 1970s were a direct result of the fact that many capable parents—mostly mothers—did not have careers. Instead, they became volunteer advocates for their own children and others. Parents were, and continue to be, the driving forces behind the legislative, judicial and attitudinal changes described in our special 25th Anniversary Issue (June 1996).

Today, at the typical American home, no parents are at home during the day. Most parents work, in both one- and two-parent families—even when one or more children have disabilities. And, because adults now live longer, many parents are also involved in the care of their own parents, grandparents, in-laws or other older relatives. As many of our readers know all too well, the 24-hour day is just not long enough!

Several articles in this issue include the stories of parents who juggle family and career with reasonable success (although we know many of our readers are far too busy juggling to write to us). Among these "success stories," understanding employers are a recurrent theme. In fact, a recent *Wall Street Journal* article noted that "family-friendly workplaces" translated into fewer employee absences and better overall work performance. We assume that these workers also "performed" better as parents and human beings.

Exciting research

When I first learned about the research reported in "Measuring Parents' Perceptions of Care-Giving," I knew it belonged in our magazine. Using the principles of family-centered care, this carefully designed scientific study demonstrates that when parents of children with disabilities perceive that they are being treated respectfully by health professionals, they report less personal stress. And further studies are showing that when parents report less stress, they have fewer stress-related health problems. This research shows that family-centered care is cost-effective—because it prevents health problems in parents.

Advertising correction

Because the information provided in advertising is so important to our readers, we have a policy of screening all advertising submitted. Ads are reviewed to determine the accuracy of claims made. We regret that in the May and June issues, this screening process failed to exclude an advertisement entitled "Focus Problem?"

Time for fun!

Family fun, excitement and education are in store at Forum '96 in Anaheim in October (see pp. 43–46) and on the Internet now (see pp. 70–71). Some copies of this issue include a survey about technology and the Internet. Please complete the survey and return it as soon as possible.

EXCEPTIONAL PARENT

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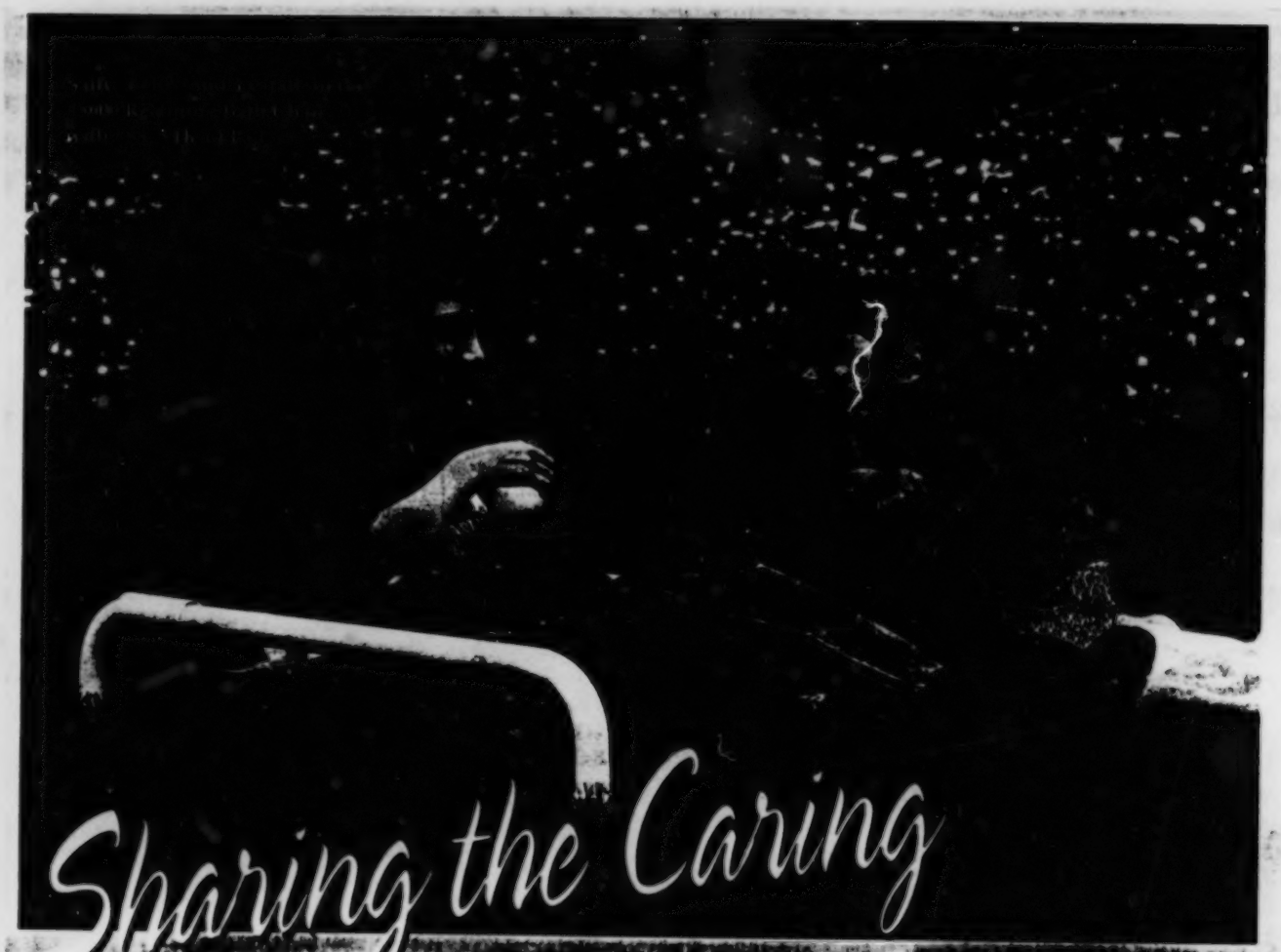
For subscription and advertising information, see page 10.

BPA



Sharing the Caring

Columbia offers you solutions to the daily challenges of bathing, toileting and transporting your child – *with comfort, safety and ease!*

You and your child face some tough challenges, but you're the one who must solve them in the most practical ways. Here's how we can help:

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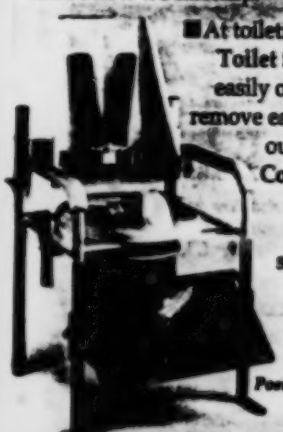

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■ At bathtime, our popular **Wrap-Around Bath Supports** and **Reclining Chairs** allow your child – and you – to enjoy the bath.

#7200 Wrap-Around Support

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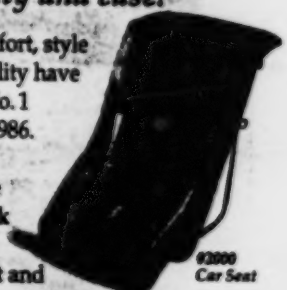

#2000 Car Seat

Why do these products work so well? Much thought and care go into the design of each Columbia product. We make each item in the **right size for your child**, with lots of adjustability for a custom fit. They are made of durable materials, proven in real life. Made in the USA and sold all over the world, Columbia products are leaders in *all* their categories.

Get all the details from our FREE full color catalog. "Sharing the Caring" means *products that work!*

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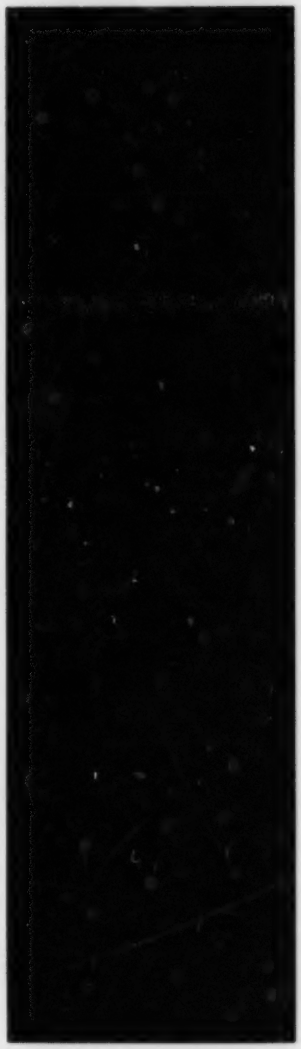

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LETTERS

Why Was Your Baby Born Early?

I agree 100 percent with Teresa Wolding's article "So... Why Was *Your* Baby Born Early?" (March 1996). I don't know how many times I've been subjected to crude remarks from strangers about my son's premature birth and its aftereffects. The March of Dimes has brainwashed most of America into believing that almost all such births can be prevented. These public service advertisements give the general public license to abuse women who are already feeling guilty for something they couldn't prevent.

I had the best prenatal care available. I followed my doctors' orders to the letter and even spent time in the hospital. Despite everyone's best efforts, Arthur William entered the world two months early to save his life and possibly mine—my diabetes and toxemia might have killed us both. He weighed less than three pounds. Fortunately, he was able to breathe on his own and needed very little specialized medical attention.

Now four and a half years old, Arthur functions more like a child half his age. He has mild hypertonic cerebral palsy, a seizure disorder, developmental delays and microcephaly. Given his premature birth, things could have been much worse. At least my son can run, play and communicate.

I once had a doctor in an emergency room tell me my son's problems were due to my alcohol abuse during pregnancy. Trouble is, *I don't drink!* He refused to believe me. I was livid, to say the least! Things have gone too far when even doctors swallow the March of Dimes line.

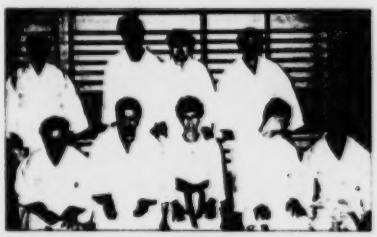
The March of Dimes owes us all a public apology. After the incident with the emergency room doctor, I called our local branch of the March of Dimes; I got a "tough beans" attitude. More recently, I called the number given in the March of Dimes statement accompanying Ms. Wolding's article. I ended up speaking with a woman in the media department, who couldn't seem to understand my objections to these advertisements; she suggested I call EXCEPTIONAL PARENT with my comments. Nobody at that number seemed to be aware that their organization had provided a statement to accompany Ms. Wolding's article, nor did anyone seem to care about what I had to say.

Yes, I am aggravated. But I have enough compassion for the misinformed to try to enlighten them about the realities of prematurity and birth defects. Arthur's disability is no more my fault than the weather.

M.B., Ohio

Karate Kids

We enjoyed Barry Atkinson's Children's Page ("The Karate Kid," October 1995) and the letter of encouragement from black belts Don and Susan Bleich ("The Karate Couple," *Letters*, February 1996). It is wonderful to hear about individuals with disabilities who have been given the opportunity to learn karate and are enjoying its benefits.



Students with disabilities enjoy both separate and inclusive classes at Kan-Do Karate in Rehovot, Israel.

Our organization here in Israel, Kan-Do Karate, is dedicated to teaching karate to individuals with various disabilities. Some students who start out in our adapted classes go on to join regular classes—for some, their

continued on page 6

CORRECTION

The article "Guidelines for Safe, Accessible Playgrounds" (May 1996) indicated that playground pathways of uniformly sized wood chips are accessible surfaces. According to the U.S. Department of the Interior, however, wood chips are not considered an accessible surface. Only three types of surfaces—rubber matting, poured rubber or wood fiber—are considered accessible to wheelchair, scooter or walker users. We apologize for the error.

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Circle #58

LETTERS

continued from page 4

first inclusive educational experience. We also train karate instructors who are willing and interested in working with students who have disabilities. For these instructors, it is often their first encounter with a population that is too frequently isolated and excluded. We are all made stronger by these encounters.

Shayna Alexander, Director
Kan-Do Karate
Rehovot, Israel

Managed Care

I thought readers might be interested in my family's experience with managed care. When my son, who has cerebral palsy, aged out of his early intervention program last year, I asked my HMO to provide him with physical and occupational therapy. They provided therapy twice a week for two months and then stopped because, in their opinion, he was not making

continued on page 8

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742, fax. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication but enables us to contact letter writers directly if necessary.

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***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

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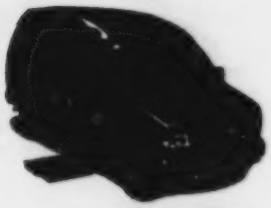

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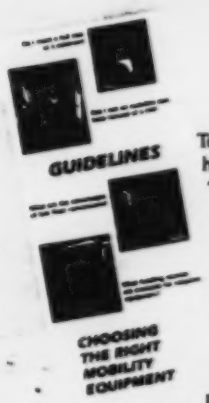

To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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Special Formulas

Texas law mandates insurance coverage

Miranda and Justin Brown, 20 months.

I could identify with the families of Haley Engleman ("Fighting for Haley's Life," February 1996) and the Evans children ("Perseverance Pays Off," May 1996), who found themselves locked into seemingly hopeless battles with health insurance companies over payment for the special formulas their children needed to survive. It wasn't long ago that I found myself in a similar situation.

My twins, Justin and Miranda, were born in September 1994. Although both twins seemed healthy, Miranda seemed to throw up a lot. Still, nobody was too concerned until, at four months of age, she lost her eyesight and the ability to turn over or lift her head. That was the start of my battles with our HMO—first to be referred to specialists for testing; later, to obtain payment for the special predigested formula Miranda's doctors prescribed after it became obvious that she could not tolerate regular foods or commercially-available baby formulas.

As a single mother, I did not have the money to pay for Miranda's very expensive formula; however, I was not yet impoverished enough to qualify for governmental assistance. "What would you have me do?" I asked the doctor. "Should I live in my car and hang the g-tube out the window?"

Unfortunately, the state insurance board concurred with the insurance company's refusal to pay for the formula. The lawyer I hired told me it was a contractual issue and struggled to find a way to argue the policy's wording.

Meanwhile, the medical director of the hospital where Miranda received her care began looking into the laws himself. To everyone's surprise, he discovered a section of the state insurance code that stated that insurance companies had to pay for formula in cases such as Miranda's—where the child had a suspected metabolic disorder, even if the child did not have a definitive diagnosis. Based on this section of the Texas Insurance Code (article 3.79), our HMO reversed its decision and now pays for the formula.

The Texas Board of Insurance told me they were embarrassed not to have realized that a section of their own insurance code applied to Miranda's case. They vowed to make it common knowledge in their office, so other families will not have to fight the same battle we did. I am also working to spread the word so this law becomes common knowledge in our state.

—Cynthia Brown
Dallas, Texas

continued from page 6

significant progress. Since his therapy has been discontinued, he has developed contractures of the leg and hip.

Our HMO does not have pediatric specialists, nor have they recommended that my son see one. He sees specialists outside the system because I take him to private doctors and pay for their services out of my own pocket. What else can a parent do?

C.M., New York

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Circle #68

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SEARCH

Building a Wheelchair-Accessible Home

Our seven-year-old son has X-linked myotubular myopathy, a rare condition that causes very low tone in all skeletal muscles. He uses a wheelchair. This summer, we plan to custom-build a new home that is more accessible for him. We are searching for parents who have done this and can share their experiences with modifications that worked well or not so well.

P.S. & G.S., Texas

Undiagnosed

Our two-year-old daughter, Lindsey, is undiagnosed. She has hypotonia (low muscle tone) and developmental delays. She sat at eight months, crawled at nine months, and walked at 16 months. Her speech and fine motor skills are also delayed.

When she was six months old, Lindsey had a variety of evaluations including an MRI, an EEG and tests for metabolic disorders; the results showed no abnormalities. Lindsey was born with an extra large fontanel (soft spot on her head) and a small dimple at the base of her tailbone. She has had chronic ear and bladder infections.

The doctors do not believe Lindsey's disabilities are of genetic origin, although they do not know for sure. We were using the sponge for birth control when I became pregnant. We would love to hear from parents with a similar child.

K.E., Arizona

Breakaway Pants?

I am an occupational therapist in a public high school. This year, the school's physical therapist and I have worked on independent catheterization with two girls who have spina bifida; both are wheelchair users. The biggest stumbling block for both is pulling their pants up, either on the toilet or in the wheelchair. They can pull their pants down, but it is time-consuming. A nearby spina bifida clinic suggested pants that split or break away down the middle seam, beyond where a zipper would typically end. I have been unable to find a source for these.

There are other complications for these girls as well, such as changing sanitary pads and incidental bowel movements while transferring. Due to space limitations and multiple bathroom locations in the school, it would not be practical to use a cot to catheterize. I would like to hear ideas from children, adolescents, parents or therapists who have overcome these difficulties.

S.S., Illinois

Little League

My 14-year-old son has Angelman syndrome, a condition characterized by mental retardation, muscular abnormalities, epilepsy and absence of speech. I would like to encourage our town's Little League organization to consider forming special teams for children with disabilities. I would like to talk with someone who has had experience with such teams so I will have the particulars when I approach our local organization.

D.A.C., Oklahoma

EDITOR'S NOTE: The Challenger Division of Little League Baseball offers children with disabilities, ages five through 18, the opportunity to participate in Little League baseball. For more information, contact Little League Baseball Headquarters, P.O. Box 3485, Williamsport, PA 17701; (717) 326-1921.

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EXCEPTIONAL PARENT
The Magazine for Families and Professionals
Parenting Your Child of Young Adult With a Disability

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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Circle #72

Making Connections

Our son, John, was just 10 weeks old when he was diagnosed with X-linked myotubular myopathy (sometimes called centronuclear myopathy), a rare genetic disorder that only affects males. Boys with this condition have very low tone in all skeletal muscles and, often, are ventilator-dependent. We were told that John probably would not live through his first year of life.

With the help of a researcher studying muscle disorders, we managed to find one other family who had a son with the same condition. Then, when John was two years old, after all our other attempts to locate additional families had failed, we decided to write a *Search* letter to EXCEPTIONAL PARENT. That 1991 *Search* letter was the start of the X-Linked Myotubular Myopathy Resource Group, which was formally established in 1994 and has now grown to more than 50 families in the United States, Canada and the United Kingdom.

Pamela Scoggin shows her son, John, 7, the photo of another child with X-linked myotubular myopathy whose family was just referred to the support group.

In just a few short years, the group has made great progress toward accomplishing our three main goals:

- **To establish parent-to-parent connections for advice, support and advocacy.** We have found that this condition is not as rare as was generally believed. Yet almost every set of parents in our group has had the experience of being told that their son is the only living case.
- **To establish a physician-to-physician network through which successful medical interventions and treatment plans can be shared.** We have learned that, with proper medical intervention, the outlook for these children is not as dismal as most professionals believe. The conventional wisdom has been that this disorder is usually fatal in the first year of life; however, of the more than 50 affected children we know of, about 40 are still alive. Members of our group have affected children ranging in age from newborn to 19 years.
- **To link families and physicians with researchers interested in this disease.** Ongoing research on X-linked myotubular myopathy is occurring in the United States and Europe. The key to finding the responsible gene and, perhaps, successful treatments lies in getting DNA samples from affected families into the hands of the researchers.

Our group publishes a newsletter containing information on useful resources, the latest research, useful equipment, successful medical interventions, prenatal testing and helpful social, medical and therapeutic programs.

We also send an information packet to interested parents and professionals and help researchers obtain blood samples from affected families. And, recently, we have embarked on a project to mail information about this condition to all U.S. hospitals with neonatal and pediatric services in the hope of helping more children get earlier diagnoses and the most appropriate medical support.

One of the most fulfilling aspects of our involvement is the many good friends we have made. Many are people we've never met, but with whom we communicate regularly by telephone, letters and e-mail. Although most of us are separated by great distances, we share the common experience of dealing with this rare disorder.

John, now 7, attends regular classes in our neighborhood school, makes all A's and is an enthusiastic Cub Scout. We feel that the resource group is a small way we can help him and all the other affected kids.

—Gary and Pamela Scoggin

FOR MORE INFORMATION
X-Linked Myotubular Myopathy Resource Group
2413 Quaker Drive
Texas City, TX 77590
(409) 945-8569
e-mail: gscoggin@aol.com
http://members.aol.com/xmtm/page1.htm

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Reflex Anoxic Seizures

My six-year-old daughter, Francesca, suffers from what doctors call reflex anoxic seizures. Any unexpected stimulus—be it a bump, fright or shock—causes her heart to stop, her complexion to become deathly white, her eyes to roll up and disappear up into her head, and her back to arch. Sometimes her arms and legs jerk; then she becomes like a rag doll and remains unconscious for anywhere from a minute to more than an hour.

These attacks began when she was a year old. They occur without warning as often as several times a day. It is very frightening. I am desperate for more information about this condition and contact with other families.

T.L., Warwickshire, England

Eating Orally

Our daughter, now four years old, was diagnosed with periventricular leukomalacia, a condition in which tissue around the brain's ventricles (chambers in which cerebrospinal fluid is made and circulated) is damaged due to insufficient blood flow or lack of oxygen. Presently, she does not eat orally.

We would like to hear from others who have successfully taught a child with this diagnosis to eat orally or who are still in the process of achieving this goal. We also welcome suggestions from professionals and recommendations for programs that specialize in feeding difficulties.

S.P., Kansas

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, *EXCEPTIONAL PARENT*, 209 Harvard St., Ste. 303, Brookline, MA 02146-5066, (617) 730-8742, fax.

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt. 37, P.O. Box 8923, New Fairfield, CT 06812, (800) 999-NORD, (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513, (800) 651-1151 (V/TTY) or (706) 632-8930.

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RESPOND

No Father's Voice

T.W. (February 1996) is the mother of two young children, one with cerebral palsy. Both she and her husband work full-time, but her husband does little in terms of caring for their son—doesn't feed, bathe, or play with him, never takes him to therapy or to doctor's appointments, and won't do exercises with him. He refuses to read anything on disabilities. T.W. is interested in family or marriage counseling, but doesn't know how she could get her husband to go. She is also worried that by going to counseling, she and her husband will be admitting they are failures. She wanted to hear possible solutions from other parents who had dealt with similar situations.

Four years ago, I could have written your *Search* letter. Like you, I am married and work full-time while raising two small children. Our son, who is six years old, has athetoid quadriplegic cerebral palsy. When I first realized our son was not progressing normally, my husband would say, "Just give him time," and tell me that I read too many child development books. Our family doctor wasn't much help either, labeling him "developmentally delayed," but refusing to refer him to specialists for further testing.

When our son was 12 months old, and still not crawling, sitting unassisted, rolling from back to stomach or babbling, I scheduled an appointment with another pediatrician. He immediately referred us to a neurologist and physical therapist. We began the typical whirlwind of tests, therapy and appointments with specialists. Just as I had always taken our son to his doctor's appointments, I was always the one to deal with these new appointments. This was partly because I *wanted* to be there, and partly because my husband seemed unable to accept what was happening.

I threw myself into the situation, doing therapy exercises with our son and trying to facilitate his progress in any way possible. My husband devoted all his extra time to community service organizations and television viewing. Although he changed an occasional diaper, he never bathed or fed our son. He did not drive him to daycare during the first two years. It was my battle with stress-related illnesses that finally led us to break some of these patterns.

Based on my experiences, here is my recommendation—get counseling for yourself. Don't wait until you can talk your husband into going. You may never be able to do that. (I wasn't.) After all, *he* doesn't have a problem with things the way they are. Through therapy, you can find ways to improve your quality of life and to change behaviors. You may find that there are other issues you are dealing with, such as feelings of guilt or worry about your son's future. A therapist can help you devise strategies for dealing with such issues. You may be referred to an appropriate therapist through a medical doctor or community mental health organization. In addition, many hospitals and rehabilitation agencies have staff social workers and psychologists who help families to make the necessary adjustments in their lives.

continued on page 15

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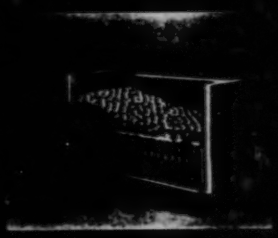

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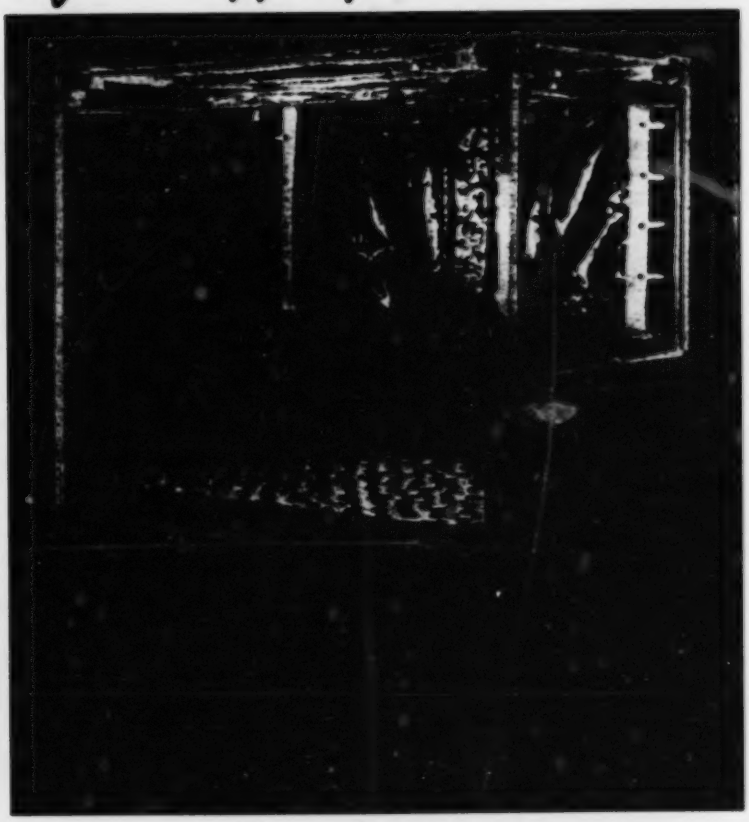

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continued from page 14

Please don't feel that you have to do it all. Just as your son needs doctors and therapists, you need a team of people on your side to help you raise him. It is difficult to consider scheduling another hour out of the week to see a therapist, but your children will benefit also. Unless your situation changes, they are bound to feel your stress and anger.

Try to take a little time for yourself each week. Of course, that's also difficult, but it would give you time to think and help you use your time with your children better. Make sure you are able to take an occasional evening out with your husband. Finding a qualified sitter isn't easy, but it would be worth it because spending time together—just the two of you—could really improve the quality of your relationship.

In our case, I believe my husband's acceptance was made easier because he had bonded with our son before he was diagnosed; it was the cerebral palsy he had a hard time accepting, not our son. But he has been able to overcome his denial, and become a partner in raising our children.

One breakthrough occurred when our son was scheduled for a physical therapy appointment, and I was unable to take off from work. Coincidentally, my husband had the day off. When I suggested that he take our son to the appointment, he asked why I didn't reschedule. I reminded him that our son would need many years of physical therapy and it's not likely I will be able to take him to every appointment.

So I talked my husband through the appointment, explaining step-by-step what happens. He brought our son to the appointment and spent the hour observing and talking to the therapist. He came home ready to talk about cerebral palsy for the first time.

Over the past several years, my husband has assumed much of the responsibility for our son's care. He has also become involved in our local cerebral palsy organization. Of course, everything in our lives and relationship is not perfect and never will be, but our son's cerebral palsy is no longer something I have to deal with by myself.

D.M., Michigan

■ You are exactly where I was not so long ago. I, too, have a son with cerebral palsy and work full-time. Until almost a year ago, I, too, did all the housework and all the tasks related to my son's care. Even going on vacation seemed like a chore since I did all the packing and continued to be responsible for our son's daily care, including tube feedings and therapy; I did everything but relax!

I was at the end of my rope and even threatened divorce. Because I was so depressed and overwhelmed, I could not manage to find a way to

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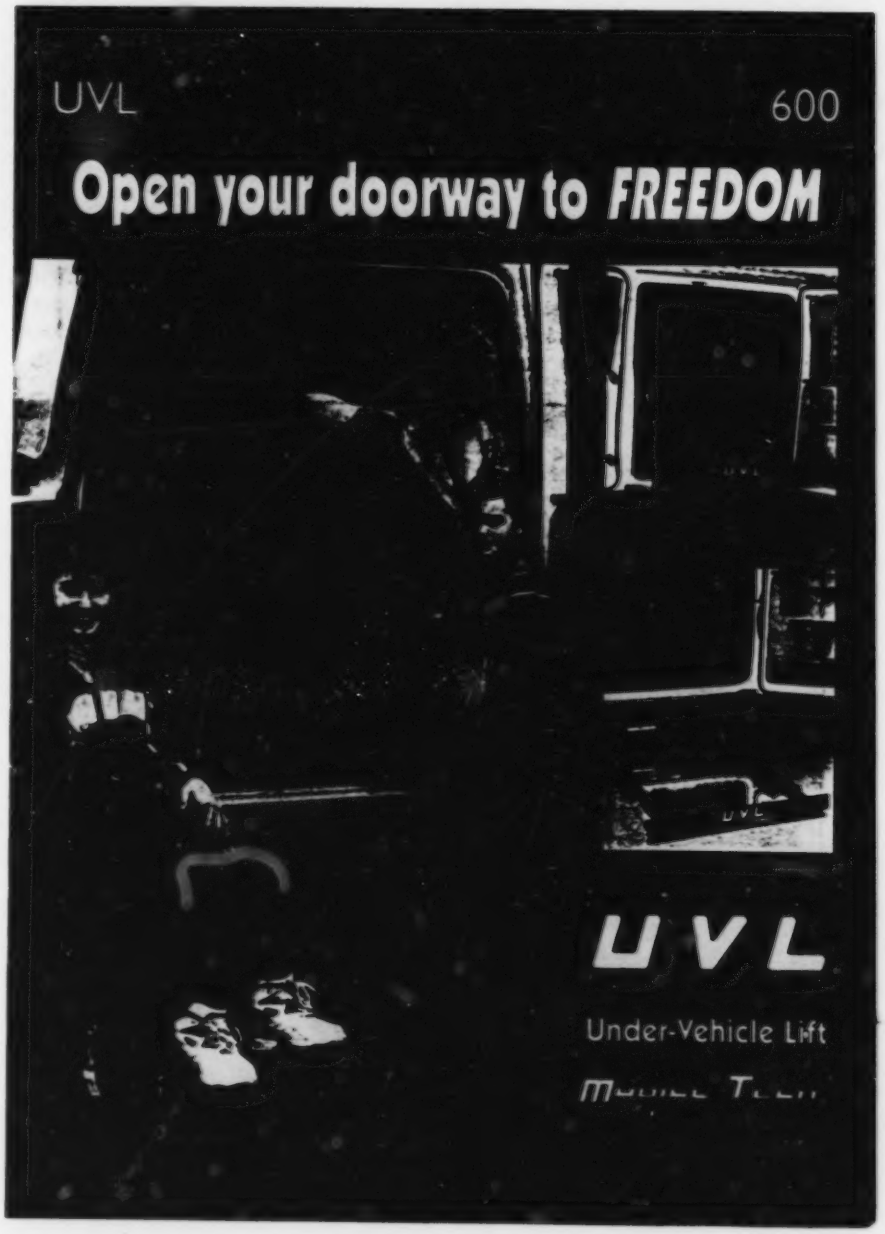

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communicate my needs to my husband without starting an argument. On the few occasions we managed to talk without arguing, his attitude was so negative, I only became more depressed.

I explained the situation to my doctor, and he referred me to a local counseling center. I started seeing a counselor by myself. I knew I needed to find a way to put my life in order and be happy again. My husband kept saying that he would see a therapist, too, but he never made any effort to find one.

Every time I came home from a therapy appointment, my husband wanted to know what I had talked about with the counselor. It was a great way to initiate a discussion.

Eventually, my husband started asking if he could go to counseling sessions with me. I resisted at first, thinking he should make the effort to find his own therapist. But soon I realized it was effort enough for him to join me. At our therapy sessions, we discovered we had so much to talk about. After each session, we would leave the therapist's office and go for ice cream just to have a neutral place to continue our discussion. We realized that we both had to change in order to salvage our relationship.

Our son was very medically fragile for his first 18 months. Our therapist helped me understand that by not being involved, my husband was protecting himself from his biggest fear—that our son might die. The more he distanced himself, the less it might hurt him. This insight really helped me; before that, I always felt that my husband just didn't care or didn't love our son as much as I did.

The therapist assigned my husband tasks to do with our son such as reading him a book. These tasks were designed to help him see our son as a child and get to know him more intimately. My husband felt awkward and silly at first, but now father and son are fast friends! Now our son constantly seeks my husband's attention—and this little boy is hard to ignore when he squeals with delight at the sight of Daddy!

I also had to learn to let go and allow my husband to assume some responsibility for our son's care. At first I had to write down detailed instructions, but eventually he learned most of the daily routine. Sure, sometimes he did things differently, but I had to learn that perfection is not always a must. Initially, I left my husband alone with our son for just an hour or two every weekend; eventually, I joined a gym and began attending aerobic classes regularly. Now my husband cares for our son every night before I get home. It is still a learning experience for both of us but I think the best part of therapy was that it taught us to communicate our concerns and reach compromises.

J.B., New Jersey

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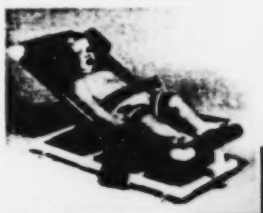

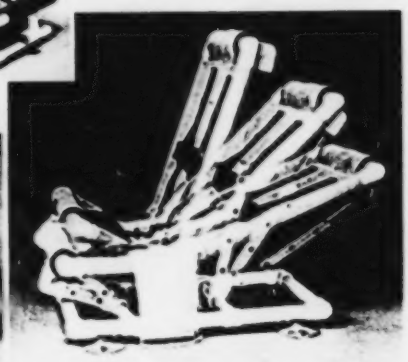

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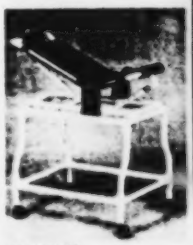

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Familiar Faces

Kimberly Fowler, 8, used to be afraid of costumed characters, so her mom, Betsy, worried about how she would handle last year's family vacation to Walt Disney World. Fortunately, she loved the whole experience—including this Disney Character Breakfast. Betsy writes, "Tigger tried repeatedly, and unsuccessfully, to coax a smile from Kimberly. As soon as he left her table, she grinned from ear to ear!" Kimberly, who has Sanfillipo A syndrome (mucopolysaccharidosis type III), lives with her family in Macomb, Michigan.

Beth Elovitz, 18, seems to be getting along spectacularly with the family's new Golden Retriever puppy, Dixie. Beth has Moyamoya disease, a condition that causes the two main arteries of the brain to contract; this resulted in a series of strokes when she was young. Beth, who uses an augmentative communication device, has already taught Dixie to respond to her hand signals. Beth lives in Skokie, Illinois, with her parents, Howard and Toby, and her sister, Geri, 22. She enjoys shopping, writing to her many pen pals worldwide and chatting on the Internet.

Five-year-old **Stross David Newcom (left) relishes his role** as big brother to eight-month-old **Skye.** "Stross is proud of all he is teaching his little brother," write his parents, Mark and Joy. Skye reciprocates by "helping" during Stross' therapy sessions; when Stross practices kicking a big red ball, Skye eagerly chases it down. Stross, who was born with spina bifida, hydrocephalus and an imperforate anus, for which he has a colostomy, loves preschool and is looking forward to starting kindergarten this fall. Stross and Skye live with their parents in Forest City, Iowa.

A relaxed but elegant **James Grady Jennings II,** 5, looks ready to carry out his ring bearer duties at a friend's wedding. James, who has Down syndrome and attention deficit disorder, attends a regular kindergarten class near his home in Ontario, California. James lives with his parents, Grady and Joann, who describe him as "a handful at times, but also an armful of love."

Their mother tells us that five-year-old **Brandon** and **Brittany Fasnacht** sometimes have trouble getting along, but you'd never know it from this picture! Both twins have hydrocephalus. Brandon also has cerebral palsy, a seizure disorder and mild mental retardation. The twins attend different public schools near their home in Phoenix, Arizona.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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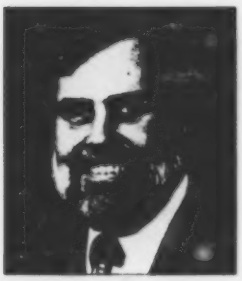

Rich Crawford

"A stockbroker needs foresight, not eyesight."

Richard Crawford, Jr. was born in Grinnell, Iowa, in 1950. He was diagnosed with retinitis pigmentosa at age three, and became legally blind by the age of 10, when he entered the Iowa School for the Blind. He graduated from Wartburg College in Waverly, Iowa, and received his MBA from the University of South Dakota. Now a stockbroker for Dain Bosworth, he is ranked among the company's top 70 brokers (out of 840). Crawford lives in Sioux City, Iowa with Sara, his wife of 14 years—he jokes that he met her on a "blind, blind date"—and their two sons, Richard Paul, III, 12, and Billy, 11. He also has a daughter, Charity, 21, from a previous marriage. The following is adapted from an interview between Crawford and EXCEPTIONAL PARENT *editorial assistant Michelle Jaeger.*

When I started losing my eyesight I was really resentful—I thought, "Hey God, what did I ever do to you?" It was a common sentiment in the fifties. Even my parents believed my blindness was a result of their sins. With counseling, they got over it.

I was lucky in a lot of ways, however. My mom and dad were parents at 15 and 16. They didn't have preconceived notions of parenthood, nor did they have experts telling them how to raise a blind child. They just used common sense. My mother didn't overprotect me—maybe because she didn't know she was supposed to.

Because I lost my vision gradually, I was just another kid for a while. I loved baseball, and my friends and I came up with ways for me to play. For example, instead of having the ball pitched to me, I would throw it up and hit it. But as my vision worsened, everything became more difficult. My last year in Little League, I missed a catch. A kid asked, "What are you, blind?" I cried all the way home and never went back.

Rich Crawford and a friend at their high school graduation. Says Crawford, "Not only did I excel in my classes, I also got involved in extracurricular activities. I was in chorus, which helped me become involved socially. I had minor roles in school plays, was a varsity wrestler and became senior class president."

Rebellious and creative

The school for the blind categorized kids as "totals" and "partials." When I started there, in fifth grade, I was considered a "partial," meaning I had some vision. This designation gave me responsibilities such as leading kids from one place to another and serving at meals. When I became a "total," I didn't want to give up those perks.

I was very rebellious and very creative. I got into a lot of trouble because I did things like passing the pepper instead of the salt and tossing water balloons off fire escapes. One time, I used the fire hose to wet down the floor outside the cafeteria. When everyone ran out after lunch, I had kids piled up against the wall three deep.

The school superintendent had this philosophy that he wouldn't punish a kid the first time he did something wrong. Poor guy... I remember him pounding the table and saying, "Crawford, quit being so creative and coming up with new things to do wrong!"

But eventually, all my pranks—not to mention my bad grades—caught up with me. When I was in ninth grade, I got kicked out of the school for the blind.

Turning point

At that point, I went to the superintendent of the Grinnell schools and told him I wanted to go to public high school. He was not impressed by my academic record—mostly D's and F's. He told me they didn't have any special teachers for blind kids. I begged. He finally relented, and I started out by earning A's and B's. I wasn't dumb; I'd just been bored at the school for the blind.

I was outgoing, so I didn't have a difficult time making friends, but sometimes I still felt the kids didn't like me because of my disability. For example, one cold January night, I was hanging out after practice for the school play. Nobody asked me if I wanted a ride. I walked home crying. When I arrived I said, "Dad, the kids

just don't like me. No one offered me a ride."

"Did you ask?" he said.

"No," I replied.

"You're crying because you didn't ask? Don't assume everyone will know your needs. If you don't ask, you can't cry. If you ask and no one gives you a ride, then you can cry."

Fate hitches a ride

At college, I majored in business administration and business education. I planned to teach and coach wrestling—I was a varsity wrestler in both high school and college—and eventually get into business. Teaching fell by the wayside because I was hired right out of school to be the assistant director of a community anti-poverty program.

The next year, I moved to Sioux City to become the executive director of the Woodbury County Community Action Agency—the youngest executive director in the country. I learned more that year than I had in four years of college. But I didn't want to do it forever. I wanted to control my own destiny and didn't feel I could do that in a government job that depended on congressional funding.

Rich enjoys a hiking trip at age 16. Still an avid sportsman, Rich enjoys pheasant hunting, downhill skiing and shooting baskets with his sons (he aims at the noise emitted by a beeper placed behind the hoop).

Fortunately, fate intervened on one of my daily commutes. I have a rather odd way of getting to work—I hitchhike. I started in college because no public transportation was available between my home and school. In Sioux City, the buses never ran on my schedule, so I continued hitchhiking.

In the fall of 1975, I was the local honorary chairman of a telethon. One morning soon thereafter, I was picked up by a man who greeted me with, "Hi, Rich Crawford!"

"Do I know you?" I asked.

"No," he said, "but I've seen you on television and read about you in the paper. I'm a stockbroker, and my firm is interested in hiring you." I thanked him for the ride and exited, thinking he was full of hot air.

But my curiosity was piqued, so I

continued on page 28

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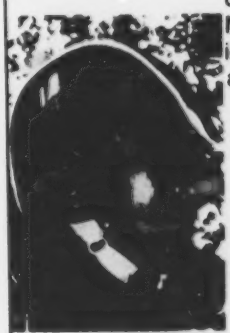

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looked him up and got an interview at company headquarters in Minneapolis. It was a risk, because I had to pay for the trip myself and would be reimbursed only if hired. When the grueling interview process was over, they noncommittally said they'd call if interested. The next morning, the local manager called and said, "We've got an uptick." In the business, an uptick means a positive response.

The decision to leave a secure job for a one hundred percent commission-based selling job was a quantum leap, but I went for it. I became the third blind stockbroker in the country. Until about five years ago, somebody read me the information I needed. Now I get market information via a visual screen that converts information to a Braille display and a scanner that converts printed material to voice.

Now, I could afford a driver, but I still hitchhike. Why? Because I get two or three new clients every month that way. I have clients in 27 states and five countries; not all of them know I'm blind. As long as I make people money, they don't care.

Why not try?

My parents instilled in me a willingness to try anything—to open my mind and overcome my fears. If I think about something I want to do, I try it. I figure if I can get my mind to think I can do something, my body can perform. For example, not only have I gone deer hunting, I've shot a deer.

It was my father-in-law's idea. I wondered how it would be possible. He set up a stand for the two of us and acted as my eyes. We went out on the opening day of deer season. Deer ran by. I tracked them by sound and got an adrenaline rush just from the sound of them running; I never realized they were so graceful and speedy. Suddenly, two does came our way. One ran past us and stopped. My father-in-law helped me aim and told me when to fire. Then he said, "You just shot a deer."

I didn't believe him. "You're a liar," I said. "If I get down there and this sucker has rigor mortis, I'll know you set me up."

We went down, and sure enough, I'd shot a deer. I field dressed it with my father-in-law's help. I got to hold all the parts—it was the best biology lesson I've ever had. The story isn't "blind guy shoots deer," it's that I thought of doing something, and I tried.

I might make blindness look easy, but it's not. It's a credit to my parents that I could learn to do things, even if I had to do them differently. You need to be willing to do more than talk—you need to be willing to act. Kids with disabilities need to learn that the price of success is hard work. I've work hard to make my dreams come true. **EP**

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JUGGLING FAMILY AND CAREER

Tales from the Supernatural

by Naomi Angoff Chedd

"You really think there are parents who can successfully manage a child with a disability, the needs of the rest of the family AND a career? Why don't you try documenting UFO sightings? You'll probably find more evidence!"

These are the words of a mother who works at a mortgage company 37 hours a week, in addition to raising three children under the age of 10—including an eight-year-old with spina bifida and learning disabilities. Like thousands of other working parents, this mother needs the income her job provides. She also enjoys her work—the challenge, the fast pace, the opportunity to spend time with "thinking adults." But she also spends a great deal of time running back and forth to doctors and therapists, special swim and gym classes and IEP meetings for her eight-year-old—not to mention playing chauffeur to her two other children, helping with homework and handling typical household crises. It all adds up to more than a full-time job for this mom and many like her.

Raising a child with a disability places enormous stress on many aspects of family life. Both parents are forced to redefine their work lives and career goals. But despite the reports of unbearable pressures, strained relationships and nonnegotiable work situations, many couples and single-parent families report that they are coping well.

How do they do it?

Many parents take less demanding jobs or decide against seeking additional responsibilities or promotions. Some report changing jobs to find one that allows for flexible hours, part-time work or job sharing. "You have to get creative," says the mother of a five-year-old with Down syndrome. "I finally got up the courage to ask my supervisor if I could work at home two days a week to be near my daughter. I outlined exactly how I would meet my job objectives, and he went for it!"

Job changes prompted by a child's disability can lead some parents to discover talents, interests and abilities in fields they might never have considered otherwise. Some find more satisfaction in another career, even if they don't always find more money. Peggy Mann Rinehart, a science writer and the mother of three children, two of whom have disabilities,

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Job Protections for Parents of Children with Disabilities

by Deborah Leuchovius

Eleven years ago, my son was born with spina bifida and a related brainstem syndrome. My employer, a small non-profit agency, allowed me to return to work part-time; my husband's income made this a realistic option. I could not have managed all my son's therapy sessions, doctors' appointments and unexpected medical crises without the flexibility this arrangement provided.

The stories I've heard since then have made me realize how lucky I was. Other parents of children with disabilities have told me of being passed up for promotions—even fired; they've shared tales of inflexible attendance policies that put them in the terrible position of having to choose between their jobs and their children's medical needs.

Fortunately, job protections are no longer just a matter of luck. Federal legislation now protects many parents of children with disabilities from discriminatory hiring and firing practices and provides for leaves of absence so parents can care for their children's special needs.

The Americans with Disabilities Act

The Americans with Disabilities Act (ADA), which applies to businesses with 15 or more employees, protects parents from discrimination in hiring and firing decisions. Simply put, an employer cannot fire you or refuse to hire you just because you have a family member with a disability.

On the other hand, although the ADA requires businesses to accommodate applicants or employees with disabilities, it does *not* require similar accommodations for parents of children with disabilities. For example, a uniformly applied attendance policy does not violate the ADA even if it has a more severe effect on employees who have family members with disabilities.

The Family and Medical Leave Act of 1993

The Family and Medical Leave Act (FMLA) of 1993, which became fully effective in February 1995, secured sorely needed leave and flexible-hour options. FMLA requires covered employers to provide eligible employees with up to 12 weeks of yearly, *unpaid* leave for personal health problems, to care for a new child added to the family through birth or adoption, or to care for "an immediate family member with a serious health condition."

FMLA applies to all private-sector businesses with 50 or more employees and to public agencies or school systems with 50 or more employees within a 75-mile area. FMLA-eligible employees have worked for a covered employer for at least 12 months, have worked at least 1,250 hours over the past 12 months, and work at a location where at least 50 other people are employed by the employer within 75 miles.

Most disabilities meet the FMLA definition of "a serious health condition"—"a chronic or long-term condition that is incurable or, if not treated, would likely result in a period of incapacity for more than three calendar days." A chronic condition is defined as one "that requires periodic visits for treatment by a health care provider, continues over an extended period of time, or may cause episodic rather than a continuing period of incapacity." In other words, FMLA leave can be used for any absence related to your child's disability as long as your child is receiving ongoing treatment from a health care provider—which may include a doctor of medicine or osteopathy, a podiatrist, a dentist, a clinical psychologist, an optometrist, a chiropractor, a nurse practitioner or a Christian Science practitioner. It is not necessary that your child actually see the health care provider each time you use FMLA leave.

Scheduling leave

FMLA leave may be taken in hours, days or weeks—in one continuous block of time or intermittently when "medically necessary." (Note: FMLA applies somewhat differently to school employees. For more information, contact your local office of the Wage and Hour Division, U.S. Department of Labor.)

You may be required to provide 30 days advance notice when your need for leave is "foreseeable." This would apply to surgeries, therapies or other procedures that can be scheduled in advance. When emergencies arise, you must give notice as soon as is "practicable."

Either you or your employer may choose to use accumulated paid vacation or sick leave to cover some or all of your otherwise unpaid FMLA leave. Furthermore, if you receive group health insurance coverage through your employer, your employer must maintain it while you are on leave.

Job guarantees

Most employees taking FMLA leave are guaranteed restoration to their previous job or an equivalent position upon returning to work. However, these protections are not guaranteed for "key employees," defined as salaried employees who are among the highest-paid ten percent of employees within 75 miles of the work site.

An employer may cite "grievous economic injury" as a reason to refuse reinstatement to a key employee. In such cases, the employee must be notified and offered a "reasonable opportunity" to return to work at that time.

For more information

ADA information can be obtained from regional ADA Technical Assistance Centers; call (800) 949-4232 (voice/TTY). For information on FMLA, call your local office of the Wage and Hour Division of the U.S. Department of Labor; the number is listed in the government-listings pages of the phone book.

If you work for a small employer who is not covered by these federal regulations, you may want to investigate applicable state or local laws. ADA Technical Assistance Centers can refer you to someone knowledgeable about state and local disability discrimination laws. And your state's Commission on Women can tell you whether or not your state has its own parental leave law. (To locate your state's commission, call the National Association of Commissions on Women at 800/338-9267.) State and local laws may provide even broader protections than federal regulations. By combining ADA and FMLA provisions with state laws, parents of children with disabilities can often weave together strong employment protections to help them keep their jobs.

Deborah Leuchovius is a technical assistance specialist at the PACER Center, Minnesota's Parent Training and Information Center. PACER (4826 Chicago Ave. S., Minneapolis, MN 55417, 612/827-2966, voice/TTY) has published a set of fact sheets on the ADA and its relevance for parents of children with disabilities. Request handout PHP-c51; $1.50.

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points out that "parents sometimes find a comfortable, professional home in the disability world." They may start out volunteering at an organization related to their child's disability, and end up taking a paying job in the field—even a leadership position. Others become so knowledgeable about disabilities and available services that their skills are widely sought by others.

Changes for women and men

Although many families seem able to achieve a comfortable balance between work and family demands, even manage two careers, others dedicate themselves to their children at the expense of their own lives. Milton Seligman, professor of counseling psychology at the University of Pittsburgh and, with Rosalyn Benjamin Darling, co-author of *Ordinary Families, Special Children*, says that many parents are willing to make considerable personal sacrifice when their children are young. "Sometimes parents feel regret later on. They feel cheated about the job they didn't go after or the trip they didn't take."

This may be especially true for mothers, who often shoulder the primary responsibility for choreographing children's education, recreational activities and medical appointments. "I honestly don't know if I would have returned to teaching if our daughter hadn't been born with multiple disabilities," says one mother. "But now I don't even have the choice."

But having a child with a disability affects men's careers too, often in profound ways. "Men are conditioned to work and support their families," says James May, Director of the National Father's Network and a family counselor in Bellevue, Washington. "It's been drilled into them since they were little boys. If they don't, they feel guilty, delinquent. But when they don't participate in their child's care—especially if that child has complex medical, emotional or developmental problems—they feel inadequate, too.

"In general, corporate America is not very family-friendly," May explains. Employees who rush off at five o'clock sharp, or who don't want

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The Perfect Job

Mark and Michael feed a giraffe at the Colorado Springs Zoo during a 1994 family vacation.

"I have the perfect job," says Susan Tachau, the mother of Carrie, 7, Julia, 10, and Michael, 14, who has cerebral palsy. Susan is a policy analyst for the State of Pennsylvania's Institute on Disabilities. She does presentations before the state legislature on issues such as managed care and the Individuals with Disabilities Education Act (IDEA). Susan also trains parents to participate in the legislative process.

"My job is flexible. I don't have to be at the same place at the same time every day, which would be impossible. I couldn't work a traditional job and still be the mother I want to be," explains Susan, who used to work at a public health organization and travel extensively. And although a big chunk of her salary goes to child care, she says that the benefits of her work far surpass its monetary rewards. "I get a lot of satisfaction in helping other people understand and deal with disability issues. Working gives me a different identity, too."

Has Michael's disability affected her husband's career too? "Definitely," answers Susan. Mark once held a high-pressure job as a bond attorney at a corporate law firm, but he now teaches at a law school, a position that allows him to spend more time with the family. "All the children have different interests and activities," says Susan. "And you can't help your kids with homework if you're working a 70-hour work week, which is routine for corporate attorneys."

Another Kind of "Active Duty"

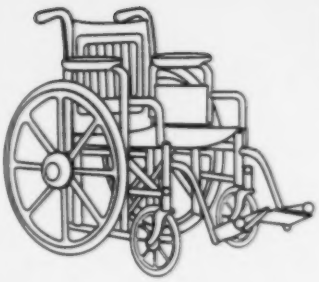
Clarence and Liz Burris live in Tacoma, Washington, with their eight-year-old son, Marc, who has autism. For 10 years, Liz served as a Captain in the U.S. Army. "My goal was to complete 20 years in the military," she says. "But I had to think about the ramifications for Marc and Clarence.

In 1992, Liz was sent to the Persian Gulf, where she spent 13 months. Clarence and Marc found her long absence a real strain, and Liz realized it was time to make a change.

So Liz got off the military career track and went back to school to study occupational therapy. "I felt I was ready to make a contribution to society in a different way," she says. While completing her degree, Liz teaches swimming to people with arthritis and back problems at the local "Y."

Clarence has also made some changes. Two months ago, he left a high-powered management job at an insurance company to set up a home office doing automobile appraisals and serving as an independent representative for a telecommunications company. "I can't put everything into my job like I used to," he explains. "Employers just don't get it. They say, 'Why can't you stay later or work weekends? Just get a babysitter.' But only specially trained people can care for our son. It's not as simple as it seems.

"I used to leave the house at 5 a.m. and get home at 7 p.m. I never saw Marc. Now I'm a bigger part of his life. Sure, I may be missing out on big career opportunities, but I have no regrets. Caring for Marc has enriched my life more than I ever could have imagined."



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to travel, may be taken off the fast track. Every business has its own set of unwritten rules and customs. If you don't play by those rules, you're less likely to get ahead.

Debunking damaging myths

Parents of children with disabilities sometimes struggle with the misconceptions of employers—for example, the belief that parents of children with disabilities are unreliable. In fact, many parents point out, the opposite may be true. Although they may need time off for appointments or medical emergencies, most are more than willing to work long or unusual hours to complete projects and assignments.

In addition, their unique experiences have given many such parents the resilience, problem-solving ability, critical thinking skills, patience and creativity to accept challenges others might abandon. As one father said, "It took me four and a half months of daily practice to teach my six-year-old daughter to eat with a fork. How many people would stick with an assignment like that? I look for every possible way to accomplish something. I never give up."

Another mother pointed to the skills she has had to develop while mastering the details of her son's very rare disorder. "I'm now the world's best researcher. Doctors have even called *me* for information about this condition."

In fact, parents of children with disabilities may have very positive effects on the workplace. These parents say they are more open-minded, less prejudiced and more philosophical about everything. One corporate executive thinks having a child with a disability has made him a more understanding and sensitive boss. The mother of a child with cerebral palsy believes that she has become a more effective psychotherapist and "a better person." And a small business owner and the father of a little girl with multiple disabilities made his building accessible, although the law didn't require it, "because it was the right thing to do."

"You can still have a life"

The Hill family: (clockwise from left) Miles, 10, Charles, Eileen, Kenan, 10, and Charlton, 8.

Eileen Hill is the mother of 10-year-old twins, Kenan and Miles, and Charlton, 8, who has cerebral palsy, mental retardation and cortical blindness. She is also a registered nurse with 20 years' experience who now works two 12-hour night shifts every weekend. Eileen and her husband, Charles, a busy salesman who works Monday to Friday, perform a juggling act to rival Barnum and Bailey's best. "It's rough," acknowledges Eileen, who changed her career plans to manage the needs of her family.

Eileen, who often works with geriatric patients, sees her children as a gift. "Raising all the boys, and Charlton in particular, has made me a more caring and skilled practitioner," she says. She also attributes her family's success to their rich spiritual life and team approach to work and family responsibilities.

Eileen points out that when a child has a disability, the whole family sometimes gets labeled "disabled." But despite his difficulties, she says, Charlton is a happy, sensitive child. "And the rest of us are very capable people—perhaps even more resourceful than the typical family."

Although Eileen admits that her work schedule cuts into some of the quality time she used to spend with her husband, she has an extraordinarily positive outlook. "You can still have a career," she says. "You can still have a life."

Making it work

The best advice always comes from those who have been there. Here is a sampling of suggestions from parents of children with disabilities who say they have been able, somehow, to manage both their kids and careers:

- *Seek out other parents* in the same situation and share ideas about how to make things go more smoothly at work and at home.
- *Use technology* to make work and home life easier. Get a car phone, a computer, a pager, a fax machine—whatever you need to help you accomplish your goals.
- *Make time for yourself.* Although it's easier said than done, it's so important to plan for a break from work *and* child care—even if it's just a couple of hours at a movie or a walk and cup of coffee with your spouse or a good friend.
- *Give up some control.* Don't be afraid to ask for help. Learn to rely on other people, whether they are family members, friends, babysitters, respite workers or health care professionals.
- *Be as honest as possible with your boss and co-workers.* Let them know you are committed to your job, but that you have unusual circumstances and need some flexibility.
- *Enjoy the present, but plan for the future.* Says one mother, "When my daughter, who has mental retardation, was a year old, I said, 'Well that's it. My working life is over.' But now it's seven years later, and she is in school most of the day. Now I want to go back to work. I wish I had thought about it a few years ago."
- *Listen to your spouse.* Support each other. Do not judge each other. Talk about your feelings and needs—including how you are going to handle the division of labor at home.
- *Laugh whenever you can.*

For many parents of children with disabilities, working often provides another much-needed dimension to their lives. "As much as I love my daughter, it's difficult being with her all the time," says the mother of a child with severe multiple disabilities. "Her progress is slow. She needs more specialized care than I can provide.

"But at work, people ask for my opinion. They listen to me. I feel valued, accomplished, rejuvenated. At the end of the day, I look forward to seeing my daughter and being her mother. Working makes me a better parent, not a worse one."

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT*'s editorial staff.*

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I Missed Some Work, but My Kid is Forever

by Charles Wasilewski

I work in corporate communications. It's my job to let people know about the many good things my company does. So, on a professional level, I was familiar with my employer's work-life program. Of course, I never expected to need such a thing personally—that is, not until my son, Michael Christopher, was born. (His name is Christopher Michael now, but that's a different story.)

We got our first surprise when the obstetrician called out, "It's a boy." Kathy and I had felt so certain that our baby would be a girl—parents' instinct, you know. We hadn't even chosen a boy's name.

The second surprise came when the pediatrician ushered me out of the delivery room and said, in his foreign accent, "Baby has webbed hand. We have called geneticist." Another jolt—an x-ray of Michael's arm and hand showed that his heart was shifted to the middle of his chest.

Charles, Kathy and Christopher Wasilewski enjoy a beautiful autumn day outside their home in Basking Ridge, New Jersey.

Charles Wasilewski and son Christopher, 3, find that Daddy's office in mid-town Manhattan is the perfect spot for viewing Macy's Thanksgiving Day Parade.

Within two weeks, we got our next stunner: Despite a regular breast-feeding schedule, Michael had gone from nine pounds, 10 ounces, to six pounds, 12 ounces, losing a third of his body weight. On a Friday afternoon, the pediatrician told us, "If you don't make baby gain weight, I will put him back in hospital."

In tears, Kathy went straight to the store and bought formula and bottles. We began feeding him formula with an eyedropper, into his mouth, drop by drop, again and again. By Sunday, I couldn't wait for Monday morning so I could go to work to escape the pressure. Kathy took Michael to the doctor; she called me at the office to say he had gained 14 ounces in three days. I call it a "miracle"—that's a technical term some of you other parents may be familiar with.

It took only 35 or 40 doctor visits before we had a diagnosis: Michael couldn't suck, or close his mouth, or blink, or smile or move his eyes laterally because he had Moebius syndrome, a rare disorder characterized by paralysis of the sixth and seventh cranial nerves. His webbed hand and shifted heart were caused by a related limb and muscle disorder.

We also learned that kids with Moebius syndrome usually have a lot of trouble forming "bilabial" sounds such as "M," "N," "P," and "B." Kathy and I looked at one another in dismay—what if he can't pronounce his own name? That's when we changed his name to Christopher Michael.

We started him in early intervention. We lived from bottle to bottle, from therapy session to therapy session. Dirty diapers were a joy; they meant he was getting plenty of formula. We listened, we watched, we learned

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Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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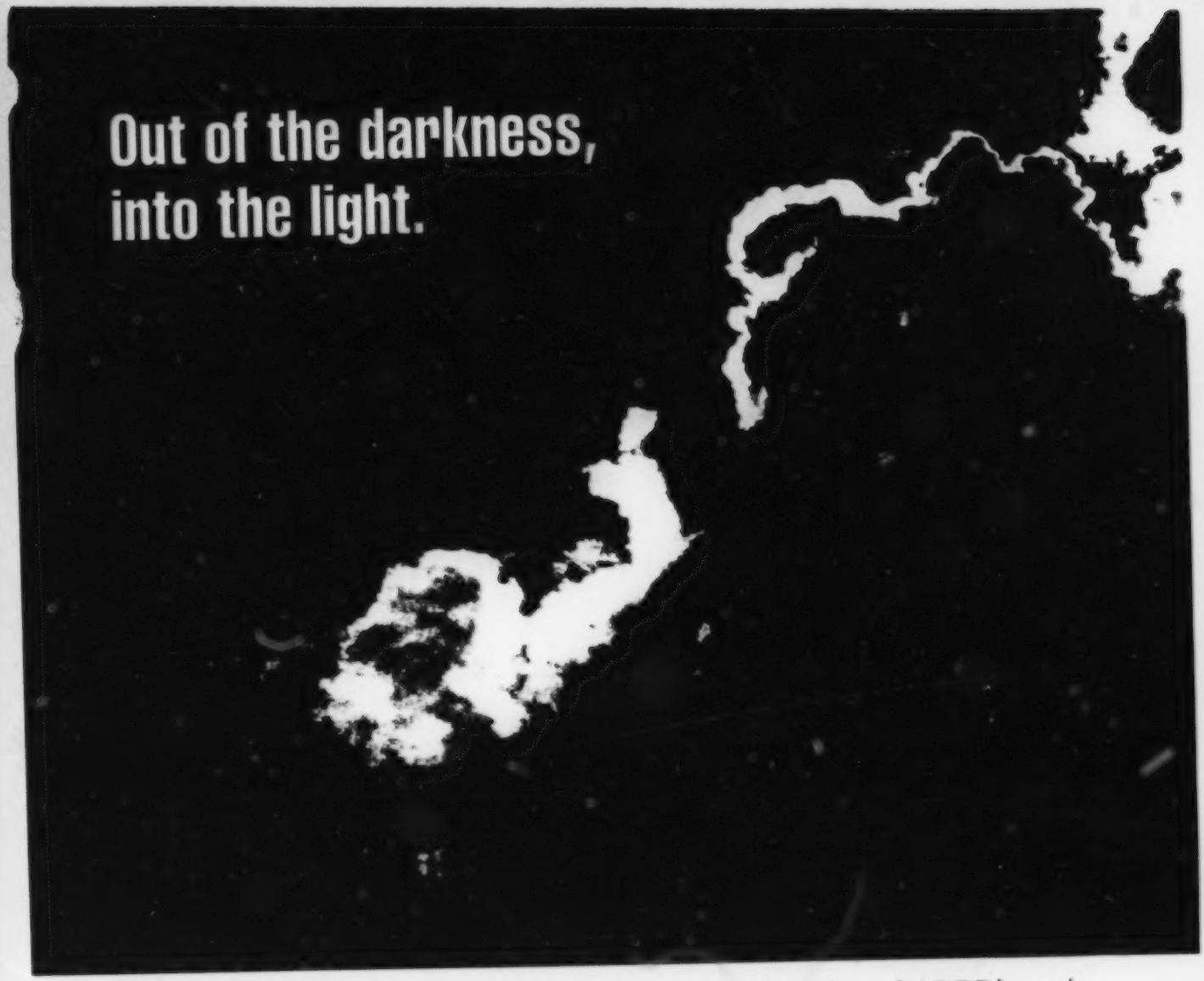

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If you are interested in receiving additional information on the conference and registration, kindly fill out the coupon below and mail to the address indicated before August 31, 1996. You may also contact NORD at 1-800-999-6673 and speak with either Jean Campbell (ext. 210) or Joseph Gatto (ext. 211). Space at the conference will be limited, so call now to guarantee a reservation!

Name: _____
(PRINT CLEARLY)

Address: _____

_____

Telephone: _____ **NORD Member:** ☐ **Yes** ☐ **No**

☐ Please send information on the 1996 NORD Patient/Family Conference.
☐ Please send information on NORD's programs and services.

Place in an envelope and mail to:
NORD • Attn: Development Office
P.O. Box 8923, New Fairfield, CT 06812-8923

Requests for conference information should be received no later than August 31, 1996.

Circle #71

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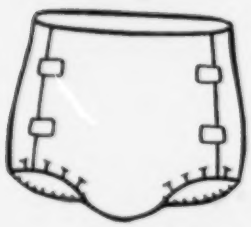

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Circle #51

Fathers' Voices

Christopher wears an appropriate hat for a day at the train show with Daddy.

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and we played with our son. We had to miss work to do it.

I never would have seen Chris learn to talk, crawl, walk, eat or drink without my employer's work-life program and my bosses' understanding. My company let me miss two half-days of work each month for two years. And through the aid of *her* employer, my wife shifted her work schedule so she was able to bring Christopher to his daytime therapy sessions twice a week.

Christopher was below the lowest percentile range in weight at six months; now, at three and a half, he's in the 90th percentile. His speech therapy is working; he has *no trouble* expressing his opinions. Oh, and he can pronounce his bilabial consonants just fine. So not to worry about him saying "Michael"—we just got the joy of naming our child twice!

I'm grateful for what my company did for my family. They understood that a family problem may last only a short time but that a kid is forever. **EP**

Charles Wasilewski lives in Basking Ridge, New Jersey, with his wife, Kathy, and son, Christopher Michael, 3. Charles works in Manhattan for Mutual of New York, where he is director of media relations. Kathy works at ADP (Automatic Data Processing) in Roseland, New Jersey. Christopher attends the Millicent Fenwick Day Care Center at the Somerset Hills YMCA.

For more information on Moebius Syndrome, contact the Moebius Syndrome Support Group, 39521 Rowen Ct., Palmdale, CA 93551, (914) 834-6008.

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DIAGNOSIS OF THE MONTH

by Karen Esperanza and Elizabeth K. Gerlach

As part of our continued commitment to keep our readers informed of state-of-the-art medical advances and terminology, Mothers From Hell has consulted specialists from Mt. Cyanide Medical Center. This month, our featured diagnosis is DDS (Dirty Dishes Syndrome):

Behavioral characteristics and other symptoms

- Shifting piles of soaking plates from one side of the sink to the other (in more extreme cases, adding fresh, soapy water each time).
- Prolonged containment of soaking children in the bathtub. Frequent result: Children ask, "Mommy, why are my fingers so raisiny?"
- Picnic and Birthday Party Obsession—Using paper birthday plates and plastic utensils for all meals. Complete avoidance of stainless steel silverware.
- Cooking exclusively finger foods.
- Consumption of instant oatmeal for lunch, with a spatula, out of a plastic juice pitcher.
- Complete reliance on frozen, microwaveable foods that come in their own disposable serving dishes.
- EPBJA (Empty Peanut Butter Jar Avoidance).
- Lid-warping or top rack dishwasher meltdown.
- Engaging in one or more of the following dishwashing avoidance mechanisms: robotic counter wiping, excessive Lazy Susan spinning or self-imposed pantry isolation.
- Hoarding recyclable products. (Note: DDS is in its most severe stages when hoarding is accompanied by excuses such as, "I might need that seven-foot pile of newspapers to dry the dishes.")
- Physical symptoms include low Mop-n-Glow tone, a red skin rash in the shape of Nebraska and disengagement from body—particularly from dishpan hands.
- Disassociation From Dishes (see also: Paperwork Pileup)—Occurs when piles of paperwork, instead of dishes, begin to fill the cupboards.
- APDR (Answering Phone when it Doesn't Ring)—Manifests itself in chronic cases only.
- Appliance Confusion—Placing dishes in the washing machine, groceries in the dishwasher, laundry in the microwave and a fork in the toaster. Other symptoms include using the wafflemaker for ironing clothes and the garbage disposal for kneading bread dough.
- Using the sink sprayer to water the flowered wallpaper.

Treatments for DDS

- *Swimming with the dolphins:* This is the most effective and proven treatment. Supporting research includes two double blind studies, a testimonial from Jacques Cousteau and an endorsement from a major tuna company.
- *Hypnosis:* There is compelling evidence to suggest that relief from DDS can be achieved through brainwashing, in lieu of dishwashing.
- *Vitamin/Mineral therapy:* Experimental research has shown that DDS patients may benefit from high doses of plutonium.
- *Behavior modification:* Successful self-help treatments include dousing self with water from the sink sprayer, shock treatments with the salad shooter, and rewarding self with raw cookie dough.
- *Crisis intervention:* A nurturing huddle around an open oven door has proven highly effective. However, appropriate dress is essential—all participants must wear aprons.
- *Escape therapy:* Efficacy of this treatment is unknown, but immediate relief is probable.

Above all, remember that early intervention is crucial in the effective diagnosis and treatment of DDS!

Karen Esperanza has written numerous articles on disability issues. She is a vocal advocate for individualized programs for children with special needs. A founding member of the Mothers From Hell, Karen's motto is "preservation through humor."

Elizabeth K. Gerlach is editor of the BRIMSTONE BULLETIN, *the quarterly publication of the Mothers From Hell. Elizabeth is the mother of two children, the oldest of whom has autism. She is the author of* AUTISM TREATMENT GUIDE *(Four Leaf Press, 2020 Garfield St., Eugene, OR 97405; $11.95 includes postage), for which the Autism Society of America presented her with a 1994 "Outstanding Parent Achievement Award."*

The Mothers From Hell is a group of women who advocate for the rights of children with disabilities. Membership (men are welcome, too) costs $10 and includes a subscription to their quarterly newsletter, *Brimstone Bulletin*. Mothers From Hell tee-shirts are $15.95 each; start-up packets, which include information on forming local Mothers From Hell groups, are $30. For information, write to Mothers From Hell, P.O. Box 21304, Eugene, OR 97402.

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READERS TALK ABOUT: Juggling Family and Career

What is Balance?

"What is balance?" This is an ongoing, soul-searching, head-scratching question that my husband, Don, and I ponder on a regular basis. We happen to be parents of a child with special needs. However, our friends whose children are just "average" ask themselves the same question daily.

My husband and I are both teachers. Four years ago, when our daughter was born, my school district granted me a one-year leave of absence. But when it was time to sign contracts for the following year, my husband and I faced a dilemma. I wanted to be home with my child while she was young. But if I chose not to go back to work, I might lose a job I loved. And then there was that not-so-little issue of health insurance—I was the carrier.

In a somewhat nonchalant manner, my husband asked what I thought about *him* staying home with our daughter. I'm embarrassed to say that this option had never occurred to me! But after mulling it over for a few days, we decided to write a letter to Don's administration requesting a leave of absence for the following school year. Although his school department had never before granted a leave of absence to a teacher—male or female—for child-rearing purposes, his request was granted! It was official; he was "Mr. Mom."

As we planned for this change, we got another surprise—I was pregnant again! When I returned to work that fall, I sheepishly explained to the principal and school superintendent that I was expecting another baby. They were both thrilled for me, and that set the tone for my second pregnancy. I appreciated their support and was relieved that my job was not in jeopardy.

At the end of that school year, our second child was born. Almost immediately, the doctors informed us that our new son had "some sort of syndrome." When Eric was six weeks old, he was diagnosed with Opitz syndrome, a condition resulting in developmental delays, low muscle tone and difficulty in swallowing (he is fed by g-tube).

Again, we needed to make a plan for child care. Because of Eric's situation, there was no question about what I had to do. Once more, I approached my administration to request a one-year leave of absence and, once more, they gave their approval.

One-year-old Eric Allen plays with one of his favorite toys—a pompom!

That year was a time of adjustment for every member of the family. Together we faced doctor's appointments, blood tests, apnea monitors, pneumonias, feeding problems and therapy appointments. The term "unconditional love" took on a whole new meaning.

All too soon April rolled around again—contract time. Thanks to his school's understanding administration, Don was once more able to take a one-year leave of absence. Through all these changes, the COBRA law allowed us to continue our health insurance through my employer; this saved us from the need to switch insurance carriers and face the problems associated with pre-existing condition exclusions that would have limited Eric's coverage. Next year, Don will go back to work full-time while I will be job-sharing with another teacher, an arrangement that allows me to work only mornings.

Although our job situation has not left us financially well-off by any means, it has allowed us to cope better with an extremely stressful two years. Our employers' flexibility and willingness to make accommodations has made all the difference in the world.

—Ann Allen
Oshkosh, Wisconsin

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT:

- **Family holidays:** How do you survive large family get-togethers when your family includes a child with a disability? What do you and/or members of your extended family do to help your family and child feel included? (October issue; deadline August 1)
- **Making connections through EXCEPTIONAL PARENT:** We know people find each other all the time through this magazine—through the annual Resource Guide, through articles; through *Search, Respond* and *Letters*; even through *Familiar Faces*. Here's a chance to share *your* "connection" story. (November issue; deadline September 1)
- **When your child grows up:** Where will he or she live, and with whom? Share your dreams, plans and concerns. (December issue; deadline October 1)

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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What a Difference a Caring Employer Can Make!

There was never any question in my mind that I would return to work full-time after my maternity leave. But when Caroline arrived, everything changed. First, she was diagnosed with Down syndrome. A week later, she contracted meningitis, which kept her in the hospital for another month. At two months of age, she had to undergo heart surgery.

After the first week of feeling helpless while Caroline was in the NICU, I decided to go back to work until she came home from the hospital, thereby saving my maternity leave for the time when I could care for her at home. Luckily, my office was only five minutes away from the hospital, so for the next three weeks, I was able to be with her for every feeding.

My husband, Phil, and I also began the process of educating ourselves about Caroline's needs. We were overwhelmed to learn about all of the therapies our daughter would require. I wondered how I would be able to return to work and still get Caroline to all of her appointments. But staying home was not an option; Phil and I needed both our incomes.

Our county's early intervention program had a one-year waiting list for nighttime sessions. It seemed our only choice was to have the therapists come to Caroline's day-care center. We did not like this option, however, because it meant we would not be present for the sessions.

After I discussed the situation with the owners of my company, they came up with a solution—they told me I could work three days in the office and two days at home. All of Caroline's therapies could be scheduled for those two days. We also agreed that if there was an emergency project that required my assistance, I would come into the office and bring Caroline along—I sometimes suspect that "emergencies" come up just so my co-workers get the chance to play with her!

Visiting Mommy's office: Six-month-old Caroline Cockrell works her charms on her mother's co-workers at PharMark Corporation, a medical software development firm in Washington, D.C. Caroline is now two years old and, according to her mother, Kim, "excelling in all her therapies."

The birth of a child with a disability results in all kinds of new pressures and worries for parents. I don't think I could have had such a smooth transition without the wonderful support of my employers and co-workers.

—Kim Cockrell
Springfield, Virginia

Work and Family

"Work and family"—some days, these words just don't seem compatible. I'm a registered nurse who works a 12-hour shift three days a week in a local hospital's busy labor and delivery unit. It is a demanding, stressful job—not unlike my job as the parent of seven-year-old Zachary, who has opsoclonus-myoclonus syndrome, a disorder involving involuntary contractions of skeletal muscles and irregular jerks of the eyes. In my son's case, the disorder was triggered by a neuroblastoma when he was almost three years old. He was left with a number of neurological symptoms including opsoclonus-myoclonus, ataxia and short-term memory deficiencies.

The rewards of nursing are both financial and emotional; it's a thrill every time I hand a new mother or father their

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Seven-year-old Zachary Meneley snuggles with his cat, Zip Zoom.

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newborn baby. The rewards of parenting are many—from seeing Zachary learn to read a new word to successfully helping him find ways to be less disruptive in class.

My husband, Guy, is my loving partner in the daily puzzle of parenting Zachary. Guy works a regular Monday-to-Friday job. On the days I work, Zach attends early morning and after-school daycare. Guy brings him to the daycare center in the morning and picks him up again after work. Then he and Zach cook dinner, play and do homework until I arrive home at 7:30.

Zach is extremely talkative and active. Guy and I must wait to communicate anything important until Zach is asleep. But we never know how long he will sleep. We take turns getting up with him. Usually one of us will arise when Zach awakes for the day at three or four o'clock in the morning. The frequent interruptions of our sleep often make it difficult to be productive at work.

Still, somehow, we manage. Here are some things that have helped:

• *Prayer:* I often pray for patience, wisdom and the physical endurance to be a good parent to Zachary.

• *Communication:* My husband and I feel less alone when we share our feelings about the fears and frustrations of parenting our son. We both feel impatient and discouraged sometimes, but usually not at the same time.

• *Families:* Our extended families sometimes offer to let Zach spend time at their house so we can have a break.

• *Information:* We read every magazine, book and pamphlet with hints on raising kids with disabilities similar to Zach's. We make lists of questions to ask his physicians, teachers and therapists.

• *Positive attitude:* We try to focus on Zach's capabilities rather than what he cannot do well. We attend parent support groups where we can share what we have learned and receive encouragement from others.

Although balancing work and family can seem overwhelming sometimes, we celebrate the small victories and enjoy the time we spend with our son. I value the evenings and weekends, and even the early morning hours with Zachary. All too soon he will be grown, and new challenges will present themselves. Until then, I'll enjoy each day of caring for Zachary—our sweet, funny, brown-eyed tornado.

—Nancy Meneley
Bryant, Arizona

A Matter of Priorities

When our second child, Melinda, was born with Down Syndrome almost 12 years ago, my first impulse was to resign from my teaching position and devote my talents to helping Melinda become "the most advanced kid with Down Syndrome ever." Without the foresight of our district's superintendent, who encouraged me to petition the Board of Education for a leave of absence rather than resigning, I would have done just that. Instead, striking the perfect balance between work and family became the central focus of my life.

Being Melinda's mother has taught me a lot about grief, compassion, empathy, motivation and just how far a parent can push a child. And nine years ago, the birth of our third child, Mary, with cerebral palsy, taught more lessons still. Mary's needs were so different than Melinda's—I needed to learn so much, so fast! Melinda had special health and educational needs; Mary's needs were primarily physical. How could I possibly do all that I needed to do for my family while continuing my career and retaining my sanity?

It still amazes me that it all works! But we've learned that the best recipe for a well-adjusted family involves putting everything in its proper perspective. For example, putting Mary through her daily therapy schedule is important, but the occasional missed therapy session is not the end of the world. Having an orderly, clean house is important, but making sure the keys on the computer are dust-free at any given time is not. We take care of the most important jobs and responsibilities first and do the less important tasks as time and energy allow. In the "big picture," what does not get done is probably not important.

Now with four children, we lovingly call our house the "Hettel Zoo." As a friend of my oldest son often says, our house is a "hectic place." But it's a fun place, too, I trust, filled with laughter of family and friends. We have our bad moments, just like all families, but we always manage to pull together and accomplish what is most important at the time—clean socks for school, happily-fed pets, dinner or finished homework. It's really pretty typical; we are more average than not.

Julie Hettel (left) takes some time off from work to visit the classroom of Melinda, 9. "I am blessed with a wonderfully supportive employer," says Julie, "but I also contribute much to my workplace and make up any time I must miss."

What a mistake it would have been for me to resign from teaching to stay home with my children. These years of juggling the demands of family and career have caused me to grow in important ways. I've become a better wife, mother and teacher with so much to contribute to Melinda and Mary, to my family as a whole, to the students and colleagues with whom I work and to the community in which I live.

—Julie Hettel
Marseilles, Illinois

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Conference Information

Hotel Single/Double $110 per night (plus tax). No charge for children under 17 sharing a room with their parents. Additional adults in the room will be an additional $25 per adult per night. As a convenience to you, the special room rate is available from Monday night, Oct. 14, through Tuesday night, Oct. 22, 1996. Call (714) 750-4321 and ask for Forum '96.

Airfare We have arranged special discounts on American and Southwest Airlines. On American save 5% on lowest applicable fares, or 10% on lowest, unrestricted coach fares, with 7-day adv. purchase. On Southwest, save 10% on their published everyday low fares. Discounts are on travel between Oct. 11 and 23, 1996. Call our official travel agency, Conventions in America (CIA), at (800) 929-4242 and ask for Group #504; or, call American at (800) 433-1790, Starfile # S6806MC; Southwest at (800) 4335368, ID#444742GR. For special rates on Alamo Rent A Car and Amtrak call CIA.

Conference Aide Save up to 70% on your conference tuition by working as an aide at the beginning and end of each day and at breaks. There are also positions available for Child Care Aides. Check box labeled "Conference Aide" on the registration form, indicate which type of aide you would like to be and include a check for $50 (tuition does not include Saturday's family dinner). Selection is on a first-come, first-served basis. Act now; positions will fill quickly.

Cancellations **Requests must be in writing.** Refunds will be given on requests postmarked no later than 14 days prior to the conference. A $35 per person processing fee will be deducted from all cancellations. Any request postmarked within 14 days of the conference will not be refunded unless accompanied by a doctor's note explaining why registrants cannot attend. If Forum '96 is cancelled by EXCEPTIONAL PARENT, tuitions will be refunded in full.

Questions?

For conference information, call IBH at (415) 851-8411 For exhibit information, contact EXCEPTIONAL PARENT, PHONE: 800.EParent.

FAX: 201 489 1240 EMAIL: epmag12@aol.com

Agenda

Thursday—October 17

7:30–9:30 PM Welcome Reception in Exhibit Hall:
Meet the Exhibitors, EXCEPTIONAL PARENT staff, and fellow attendees.

Friday—October 18

9:00–10:15 AM Welcome Address and Keynote Panel I:
Future of Family Healthcare for Those with Disabilities

10:30-11:30 AM Keynote II:
The Role of Sports and Play in the Development of Children with Special Needs

11:30 AM–1:00 PM Cash Lunch (on your own) in Exhibit Hall

1:00–2:45 PM Session I: Workshops & Roundtables

Estate Planning for Families	Ask the Doctor	Transporting Children with Disabilities	Fathers of Children with Special Needs	Inclusion: Pros & Cons	Transition Services

3:00–5:00 PM Session II: Roundtable Discussion

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

Saturday—October 19

8:30–10:00 AM Keynote Panel Discussion:
Who Should Be President of the United States?

10:15–12 NOON Session III: Workshops & Roundtables

People with Disabilities: Religion & Faith	What Happens When My Child Grows Up?	Bringing New Products to Market	Family Issues	Alternate Therapies	Children with Carnitine Deficienc

12 NOON–1:30 PM **Cash Lunch (on your own) in Exhibit Hall**

1:30–3:00 PM Session IV: Workshops & Roundtables

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

5:00–? PM 25th Anniversary Dinner & Disneyland
A fun evening of food, mingling, entertainment...and then rides and games in Disneyland. (Transportation not included)

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Agenda

Sunday—October 20

8:30–10:15 AM Session V: Workshops & Roundtables

- Making it Easier to Travel
- Ask the Doctor
- Role Models
- Fathers of Children with Special Needs
- Inclusion: Pros & Cons
- Disability Issues & the Hispanic Community

10:30–12 NOON Special Closing Forum for Parents and Children

Optional Events

Thursday—October 17

2:00–4:00 PM Pre-Conference Workshops ($45 per person)
(Choice of one)

- Funding & Where to Find It in Calif.
- Seating & Positioning Issues

Friday—October 18

7:00–9:00 PM Prominent Guest Panel Discussion: ($25 per person)
Well-known Personalities who either have Disabilities themselves or have Family Members with Disabilities or Special Health Care Needs

Registration

The following are the registration hours attendees can check into the conference.

Thurs.—10/17	1:00–9:30 PM
Fri.—10/18	7:30 AM–7:30 PM
Sat.—10/19	7:30 AM–3:00 PM
Sun.—10/20	7:30–9:00 AM

Exhibit Hall

The following are the hours the Exhibit Hall will be open.

Thurs.—10/17	4:00–7:00 PM
(Conf. Attendees Only)	7:30–9:30 PM
Fri.—10/18	10:30 AM–5:00 PM
	7:00–9:00 PM
Sat.—10/19	9:00 AM–3:00 PM

Exhibit Hall Admission

Free to all conference attendees. Exhibit Hall Only Passes: $5 per day (children under 2: free). Purchase passes at the Exhibit Hall.

NOTE: All events and schedules are subject to change.

Invited Faculty

Honorable Edward M. Kennedy,
United States Senator
Ranking Member/Senate Committee on Disability Policy

Honorable Bill Frist,
United States Senator
Chair/Senate Committee on Disability Policy

James May, MA, MEd*
Project Director, National Fathers' Network

Rick Rader, MD*
Director, Institute for Developmental Medicine
Orange Grove Center

Ginny Thornburgh
Director of the Religion & Disability Program
National Organization on Disability

Judith E. [illegible]
Asst.
US D[illegible]

Zan
P[illegible]

David Hirsch, MD*
Pediatrician, Columnist
Phoenix Pediatrics

Stanley I. Greenspan, MD
Clinical Prof. of Psychiatry & Behavioral Pediatrics/George Washington Univ. Med. Sch.

Patty Smith, Executive Director
National Parent Network on Disabilities

Stanley D. Klein, PhD*
Editor in Chief, EXCEPTIONAL PARENT

Polly Arango, Executive Director*
Family Voices

Jim Santos*
Immediate Past Family Director
Special Olympics International

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John Kemp, Executive Director
Very Special Arts

Lou Shaw, TV & Video Producer*
Producer of TV show "Quincy"

Kerry McKenna*
Transition Site Coordinator
Hudson Valley

Charles S. Lauer*
Publisher, Modern Health Care
Author and Lecturer

Anne E. Gimbel, Executive Director
Assistance for Babies & Children with Carnitine Deficiency

Peggy R. Borum, PhD
Professor of Human Nutrition
University of Florida

[illegible] Executive Director*
[illegible]

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Registration Form

1st Adult:

Name _____

Address _____

City _____ State _____ Zip _____

Phone ( ) _____ Fax ( ) _____

2nd Adult:

Name _____

3rd Adult:

Name _____

4th Adult:

Name _____

Children: (See Special Needs box)

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Conference Tuition Includes:

- Admission to all roundtables, workshops, and events
- Unlimited admission to the exhibit hall
- 25th Anniversary Family Dinner Get-Together
- Saturday evening Disneyland Park pass
- Continental breakfast each morning
- Thursday evening Welcome Reception in exhibit hall
- Refreshments at breaks
- All conference materials
- A certificate of conference participation
- A conference T-shirt
- Discount coupon for the next EXCEPTIONAL PARENT Conference
- $5-discount off your next EXCEPTIONAL PARENT Library purchase

Special Needs???

1) Will you require wheelchair accessible transportation? _____

2) What other special needs do you have? _____

_____

_____

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❑ 1st Adult	$165	$245	$_____
❑ 2nd Adult	$125	$195	$_____
❑ 3rd Adult	$95	$150	$_____
❑ 4th Adult	Free	Free	$_____
❑ Each child under 14	$65 ($65 x # of children)	$75	$_____
❑ Conference Aide	$50	$50	$_____

See "Conference Aide" under the Conference Information section
Check one: ❑ Administrative Aide ❑ Childcare Aide

❑ Special Family Rate $350 N/A $_____

Receive this special rate when you register and pay for your family of four (2 adults and 2 children under 14) by 7/31/96

Extra-Cost Events:

❑ Pre-Conference Workshop (Thurs) ($45 x # of attendees) $_____

❑ Fri. Evening Prominent Guest Panel ($25 x # of attendees) $_____

SAT. DINNER/DISNEYLAND PASSES (for non-conference attendees)

❑ Adult ($50x ____) ❑ Child ($35 x ____) $_____

TOTAL PAYMENT ENCLOSED (U.S. funds) $_____

All tuitions must accompany registration

METHOD OF PAYMENT

❑ Check enclosed made payable to Exceptional Parent (U.S. Bank)

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No Longer an Exceptional Parent

by Esther Epp-Tiessen

On October 31, 1994, our precious son Timothy died peacefully after a five-year battle with brain cancer. During his eight years of life, Tim also struggled with cerebral palsy, epilepsy and a stroke that left him with a visual impairment and cognitive disabilities. But despite his health problems, Tim was a happy child who chattered, sang, laughed and loved with much intensity.

When Tim died, a big part of me died, too. I felt like something had been ripped out of me, leaving a gaping hole. My self-identity was shaken to the core. Part of my grieving process has been figuring out who I am without Tim and accepting the fact that I am no longer the mother of a child with special needs—that I am no longer an "exceptional parent."

Dealing with emptiness and pain

With Tim's death, life changed radically and suddenly for our whole family. Appointments with medical specialists, therapists, teachers and social workers ended. Respite providers and special service workers stopped coming to our house. Tim's anticonvulsants and growth hormone medications sat in the cupboard gathering dust. There were no more forms to fill out for special equipment or the monthly income supplement for families like ours. We no longer rushed through Monday night dinners so my husband, Dan, and I could get to our parent support group meetings.

Over the years, Tim's repeated setbacks had filled us with much fear and anguish. Although Dan and I loved our son deeply, I must admit there were times when the responsibilities involved in caring for him, looking after our other two sons, earning a living and going to school (Dan was working on a Ph.D. during this time) combined to feel overwhelming.

Even so, the emptiness that came with losing Tim has been a much deeper and more intense pain than any we have ever experienced. And part of the pain is the loss of a way of life. Despite the difficulties of caring for Tim, there is much that I miss about parenting a child with multiple disabilities.

I miss the visits to our pediatrician, a caring and gentle man who looked after Tim for the eight years of his life. I miss the parents in our support group (we have since joined a bereaved parents group). I miss the appointments at the cancer clinic, always followed by a trip to the cafeteria for a treat of yogurt or french fries. I even miss some of the special "perks" that go with having a child with a disability, like attending the annual Sunshine Foundation picnic or being able to utilize handicapped parking spots.

"Tim was a happy child who chattered, sang, laughed and loved with much intensity," writes mom, Esther Epp-Tiessen. Tim loved to listen to music, take walks and have stories read to him. He was also fascinated by machines, trucks and motors—particularly by the sounds they made. Tim, shown here at age six, died in 1994 after a long struggle with brain cancer.

Saying good-bye to a way of life

Soon after Tim died, I realized that accepting his death meant saying goodbye to a way of life that had become an integral part of me.

One of the first things we did was to give away some of his equipment—his walker, his stander and some of his special toys. We decided to keep his

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wheelchair for a time, since there were so many powerful memories associated with it. When we moved it to the basement from its spot by the front door, we recalled the many places we had gone with Tim and his chair, the camping trips we had made, the bumpy paths we had "hiked" and the time we attached wings onto the chair to complete Tim's angel costume for the Sunday school Christmas program. Eventually, we will give the chair away as well.

As a way of bringing closure to some relationships, it was important for me to write or visit special doctors, teachers and others to say a final thank-you and good-bye. I also needed to make pilgrimages to the hospital where Tim had spent so much time and to the school he had attended. These were significant ways of ritualizing an end to my own relationship with these people and places.

(from left) Chris, Mark and Tim pile in for a ride in Dad's wheelbarrow.

Timothy's gift

But Tim's death has not meant completely closing the door on a world that he allowed me to enter. One symbol of this is the ramp that leads to our front door. Our family no longer needs this ramp, yet we have chosen not to dismantle it. It remains as a way of saying to ourselves and to others that our home continues to be a place where people with disabilities are welcome.

Some of the people who worked with Tim have become good friends of ours. I have kept in close contact with the treatment center where Tim received

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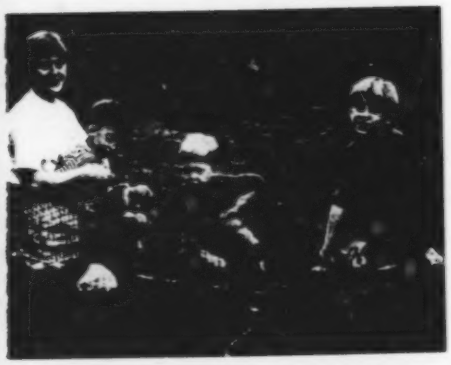

Esther and her sons, Tim, 8, Chris, 4, and Mark, 10, have fun pet-sitting Funky the rabbit and Squeakers the guinea pig.

continued from page 48

physical and occupational therapy for many years and was recently asked to serve on its board of directors. I hope that eventually I will be able to do some volunteer work there—at this point, it is still too painful to be near other children with disabilities.

Even more important are some of the lessons I learned as a result of Tim's presence in my life. From Timothy I learned about the amazing strength of a seemingly weak and fragile body. I learned about accepting tragedy and misfortune and moving on. I learned about delighting in the simplest pleasures of life—the smell of cookies baking, the taste of a juicy hot dog, the wail of a fire engine siren. I also learned about trust and forgiveness and unconditional love.

I could forget these lessons, and sometimes I do. But I also realize that they only have value if I integrate them into my own life and let them influence my relationships with the people around me now.

I am no longer an exceptional parent. Yet I am a very different person than I was nine years ago. The gift of Timothy's life has changed me in a profound and enduring way. And that is something exceptional that can never be taken from me. **EP**

Esther Epp-Tiessen lives in Waterloo, Ontario with her husband, Dan, and sons, Mark, 11, and Christopher, 5. The family enjoys spending time together outdoors—camping, gardening or just playing a game of baseball. Esther works as the Peace and Justice coordinator for the Mennonite Central Committee.

Tim and his dad, Dan, watch and listen to birds.

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Reprinted from EXCEPTIONAL PARENT, *June 1994*

Remembering Daniel

by Nathan Reiff

I once had a brother. His name was Daniel Jordan Reiff. He died at age five and a half. He had pyruvate dehydrogenase deficiency. He was my absolute best friend.

When Daniel was two years old, he could say 50 words. Then, he got sick and lost all his words except for "Naa Naa" (his name for me), "Mama" and "Daddy." He crawled a lot—so much that my little sister called him a "crawl boy." I loved him a lot, even though he had a disability. Sometimes, I felt lonely because none of my friends had brothers like Daniel. He was really, really hard to take care of and it took a lot of time, but I still loved him.

Seven-year-old Nathan (center) cuddles with baby sister Rachel, 18 months, and brother Daniel, 4.

After school one day, when Daniel was in the hospital with mononucleosis, my friend's mom came and took me to the hospital. Then, my mom told me to say good-bye to Daniel because he wasn't going to make it through this hospital stay. I said good-bye and I kissed him. At 7:20 p.m., on May 3, 1993, he died. I knew this was going to happen, but I was not ready for it. I was at my aunt's and uncle's house when he died.

Daniel's funeral was on May 8. It was my idea to put lilacs in his casket because they were just blooming. I also put in a note that said how much I loved him and missed him. I was not only sad; I was also angry.

That was one long year ago. Back then, many changes were arising. We lost Daniel, and we moved from Lynnwood, Washington to Eugene, Oregon. We did not have friends or relatives in Eugene. It was a hard time for me.

Now, I am doing better. I have some good friends, and I'm seeing a counselor. I still feel a little bit of regret about moving. I mean, there's only so much an eight-year-old can handle at one time!

Daniel Jordan Reiff, five years old.

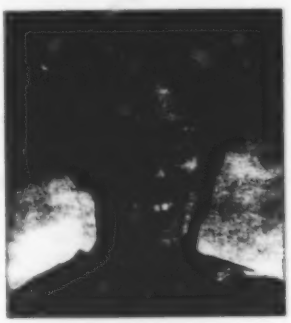
Even with all of those things helping me, I still am not totally okay about Daniel dying. As I said before, he was my absolute best friend. I will never have a best friend exactly like him again. I *really* miss you, Daniel. **EP**

Two years ago, I wrote an article for EXCEPTIONAL PARENT about my brother, Daniel. I wrote about him dying and how I dealt with his death. I wrote about our times together, good and bad. I wrote about everything. Now, I will tell you what it is like now:

I am 11 years old and soon to be a sixth grader at Roosevelt Middle School in Eugene, Oregon. I live with my mom, Ginny; my dad, Bud; my five-year-old sister, Rachel; and a snake, two cats, a dog and some fish. My hobbies are reading, writing, acting, soccer, math and playing the cello. The memorial garden our family planted for Daniel is flourishing.

This past school year, I had a very strict teacher. I had to work like crazy! In the midst of all this work, I was reminded of some very important memories of my brother. I wrote a poem about Daniel. I also wrote an autobiography. One chapter is called "Living with Daniel," and this is an excerpt:

> ...Daniel was so medically fragile that he could go from his normal state to needing ICU care in one hour. Therefore, I never knew when I went to school in the morning if Daniel would be OK when I got home. That made me very worried. I was worried about where I would go if Daniel got sick, what my parents would do and, for that matter, what might happen to Daniel.
>
> ...When I was three and a half years old, I had to learn how to help put Daniel's nasogastric tube down when he would pull it out. He needed it 24 hours a day when he was sick or, most importantly, when his lactic acid level got too high. The only way to keep him alive was by getting enough sodium bicarbonate into him through the NG tube... You can see I had to do things and live with things that other kids will probably never see or do in their lifetimes.



When Daniel wasn't sick, I had fun with him. I loved to roll around with him on the ground, take him for walks and go with him for ice cream. I loved my brother a lot, and I wish he was still with us. I hope you have learned of my love for Daniel by reading these two pieces of work.

—Nathan Reiff, Eugene, Oregon
June 1996

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The Kid-T-Racer is a lightweight, three-wheeled stroller designed for active parents who want to include their children in running, walking, hiking, shopping and other recreational activities. This folding stroller adjusts to accommodate a child's growth and features padded therapeutic seating, a sun shade, a padded lap belt, a storage pouch and 12-inch wheels with pneumatic tires. Optional positioning components, including an adjustable tray and head supports, are also available.

Kid-Kart, Belgrade, MT 59714

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TRUE FRIENDS

True Friends is a computer program that simulates a coloring book, where animal characters depict familiar childhood experiences. Characters originate from different countries and two have disabilities. The DOS-based program can be used on IBM PC-compatibles. It can be controlled with the keyboard or a single switch. The soundtrack features children's voices talking about the value of friendship.

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R.E.A.L. Designs, Dolgeville, NY 13329

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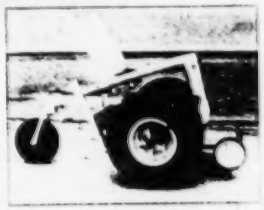

Available in three- and four-wheel fixed-frame models and a four-wheel recliner, De-Bug Beach Wheelchairs feature PVC plastic pipe frames with stainless steel hardware, all-terrain, large front wheels, swiveling rear wheels, independent suspension systems, seat belts, and wheel locks. Both four-wheel models also include a swiveling umbrella holder. Optional accessories and equipment include a ratchet-drive self-propulsion system, a custom umbrella, customized seating, removable armrests, a chest strap and a fishing pole/drink holder.

Deming Designs, Pensacola, FL 32503

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The Tumble Forms Cricket Walker is an adjustable, pediatric, prone training walker with a contemporary design. Designed to accommodate children from two to eight years of age, this walker encourages users to simulate walking movements, serving as a link to more advanced walking aids. Available in small and large sizes, the lightweight, compact walker also offers an optional padded, saddle-style seat and chest support.

Sammons Preston, Inc., Bolingbrook, IL 60440

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 58) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Measuring Parents' Perceptions Of Care-Giving

by Peter Rosenbaum

Over the past 20 years there has been an increasingly strong focus on family-centered care for children and youth with long-term health care needs. For us, the term "family-centered care" refers to a model in which professionals operate from several basic assumptions about parents and families: 1) that parents know their children best and want the best for them, 2) that each family is different and unique, and 3) that the child's well-being is affected by the stress and coping of other family members. From these premises, health care professionals can derive several guiding principles for the delivery of care—that parents should have the ultimate responsibility for decision-making and care, that each family and each family member should be treated with respect, and that the needs of all family members should be considered as each is encouraged to become involved in the child's ongoing care. But despite a growing movement among health care professionals to incorporate these principles into everyday practice, most clinical research and quality-of-care studies still look at "medical" and "technical" outcomes, rather than investigating the care-giving process itself.

At the Neurodevelopmental Clinical Research Unit at McMaster University in Hamilton, Ontario, Canada, we have been interested in the relationship between parents' perceptions of the care they receive at children's rehabilitation centers and parents' emotional well-being. We have long believed that the way care is offered to families may, at its worst, add to parents' distress, anxiety and worries; while family-centered care that is sensitive to parents' needs may prevent the development of some of these emotional difficulties.

Dr. Peter Rosenbaum greets three-month-old Taylor Sauer as her mother, Kelly, looks on. (Photo: Peter Foulds)

Developing MPOC

Before we could study the extent to which medical and therapeutic care-giving practices reduce or add to parents' stress and worries, we needed to find a way to measure parents' perceptions of the services their children received. To accomplish this task, our research group developed a questionnaire we called the Measure of Processes of Care (MPOC). We believe that MPOC (we pronounce it "em-pock") is the first reliable and well-validated instrument to look directly at what parents actually experience in their interactions with care-givers. And since MPOC measures many of the defining concepts of family-centered care, it can also be used to measure the extent to which health care and therapeutic services are family-centered.

MPOC consists of a 56-item questionnaire that asks "to what extent" parents experience a variety of health provider behaviors. Parents answer each item using a seven-point scale where "1" means "never" and "7" means "to a great extent." The 56 items are broken down into five sections, or scales, which are scored separately to reveal a profile of patterns of services:

- The **Enabling and Partnership** scale indicates parents' perceptions of their involvement in the care process. The 16 items in this scale describe caregiver behaviors such as providing parents with opportunities to make decisions about treatment, explaining treatment choices fully and allowing parents to choose the way information is provided.
  Example: *"To what extent do the people who work with your child... trust you as the 'expert' on your child?"*
- The **Providing General Information** scale focuses on activities that meet parents' needs for information about services. This nine-item scale includes care-giver behaviors such as providing information, providing advice on how to get information and providing information about community services.
  Example: *"To what extent do the people who work with your child... have information available to you in various forms, such as booklets, kits [and] videos?"*
- The **Providing Specific Information About the Child** scale includes five items that assess details of information provided about the child's test results, treatment program and progress.
  Example: *"To what extent do the people who work with your child... provide you with written information about your child's progress?"*

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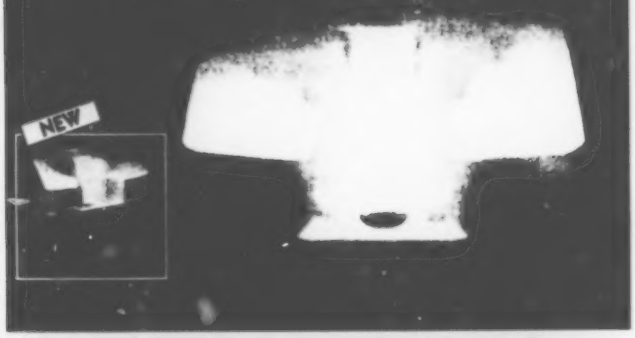

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- The **Coordinated and Comprehensive Care for the Child** scale includes 17 items that address the extent to which care is continuous and consistent over time, settings and people. It also looks at whether care is provided for the whole child and family, rather than just addressing the "technical" aspects of the child's disability.
Example: *"To what extent do the people who work with your child... plan together so they are all working in the same direction?"*
- The **Respectful and Supportive Care** scale addresses behaviors that reflect whether parents feel they are treated with respect as individuals, equals and experts. This nine-item scale asks about care-giver behaviors such as providing enough time to talk, so parents don't feel rushed.
Example: *"To what extent do the people who work with your child... help you to feel competent as a parent?"*

Reliable and valid

Before we can trust the results of research done with any measurement tool, it is important to know that it has been appropriately developed and field tested. In the case of MPOC, we wanted to be sure that we had a tool that was both "reliable" and "valid."

MPOC was developed and field tested with approximately 1,500 parents of children with disabilities who attended 13 publicly funded children's treatment centers across Ontario. Most of these children had a disability such as spina bifida, cerebral palsy or a neuromuscular disease; they ranged in age from infancy through late adolescence. We also field tested MPOC with more than 200 families whose children were receiving care in the Cleft Palate Program at McMaster University.

Our field testing has shown MPOC to be *reliable*. That is, parents answer MPOC the same way after an interval of three to four weeks. This makes us confident that our measurement of their experiences is probably an accurate representation of that experience.

We also know that MPOC is *valid*, which is to say that it seems to be measuring "the right thing." There is a strong positive relationship between the way parents answer the five MPOC scales and their overall satisfaction with the care and services they receive at their child's treatment center. Thus, when MPOC scale scores are lower, parents also tell us that they are less satisfied with their children's care; when MPOC scale scores are higher, parents generally express more satisfaction. We believe MPOC gives us a way to "get below the surface" of parents' overall judgments of satisfaction or dissatisfaction, so we can understand the care-giver behaviors that lead to these feelings.

Perceptions of care and stress

Our initial field tests of MPOC resulted in another intriguing result—we found an inverse relationship between MPOC

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scale scores and the amount of stress parents told us they had experienced over the past year in relation to the care provided at their child's treatment center. In other words, lower MPOC scale scores were associated with greater parental stress, while higher scores were associated with less stress. This suggested that our initial hypothesis was correct—that better, more family-centered care is associated with less parental stress, while poorer care increases stress.

A recently completed study confirms and extends this result. That study involved 164 parents of preschool children, with spina bifida or cerebral palsy, who attended six children's treatment centers in Ontario. This study revealed the same relationship between MPOC scale scores and parental stress, even when taking into account a number of other potentially stress-producing elements of those parents' lives—things like financial problems, marital problems and child behavior problems. We also found the same strong, positive relationship between MPOC scales and parents' expressed satisfaction with the care and services their children were receiving.

Looking to the future

We believe MPOC is an instrument with wide applicability and hope that its usefulness will be expanded by future studies. Our current plans include an attempt to replicate and extend our earlier findings with a large, international survey of parents who have children with a wide variety of medical and developmental differences.

We also hope to find out whether MPOC is sensitive enough to detect changes in care-giving over time. This would allow service providers to use MPOC to evaluate the impact of new ways of providing services: for example, MPOC could detect changes in parents' experiences following changes in a program's structure, content or style of care-giving.

MPOC could also be used to "follow" families of children with disabilities or chronic health care needs over time, starting at the time those conditions are first diagnosed. We could analyze MPOC scale scores in relation to parents' physical and mental health. This would help us learn more about the types of care-giving practices that lead to greater well-being of parents and children.

We are also beginning to develop a version of MPOC that can be answered by health care professionals to measure their own behaviors. We hope MPOC will be widely used by health professionals interested in understanding and measuring the family-centeredness of the services they provide. **EP**

Peter Rosenbaum, M.D., is a professor of pediatrics within McMaster University's Faculty of Health Sciences and a National Health Scientist funded by Health Canada, the Canadian government's health agency. Dr. Rosenbaum divides his time between clinical work with families of children with neurodevelopmental disabilities, clinical research and teaching. His collaborators on the MPOC studies are researcher Gillian King and research coordinator Susanne King.

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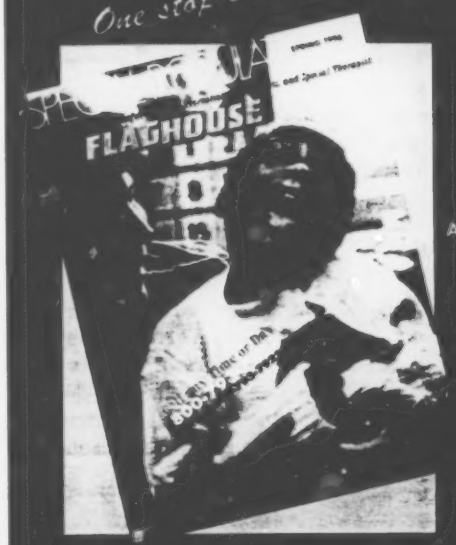

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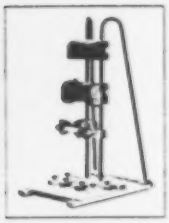

From left to right: the **Prone Stander,** manufactured by the Equipment Shop (see ad on page 54); the **Mulholland Rocket Stander,** manufactured by Mulholland Positioning Systems (see ad on page 57); the **Kidstand Hydraulic Standing Frame,** manufactured by Prime Engineering (see ad on page 57); the **Gazelle,** manufactured by Snug Seat (see ad on page 14); the **Adjustable Standing Frame,** manufactured by Rifton (see ad on page 57); and the **TriStander 45,** manufactured by Tumble Forms (see ad on page 35).

Standing Equipment

By Linda Hillyer

Many children with physical disabilities need "positioning" assistance to be comfortable while lying down, sitting or standing. Positioning aids range from a properly placed ordinary pillow to individually designed "seating systems" or standing equipment—the focus of this article.

Properly positioned, a child usually has sufficient postural support to pay attention to activities without worrying about falling; he or she will also have better control of hand, arm, leg, trunk, neck and head movements. Proper positioning may improve circulation, respiration (breathing) and digestion; stretch tight muscles and strengthen underused ones; and prevent some physical deformities and/or skin problems.

Benefits and features

For a child who spends a great deal of time seated or lying down, standing regularly can provide the physical benefits described above.

Regular standing also appears to improve the size and quality of bones and improve the formation of hip joints, especially in children who begin using standing equipment early. Professionals also believe that standing can help children develop better balance and head control as well as learn more about their environment. Standing can also improve social interactions when children can enjoy activities at the same eye level as peers. For some, this may be the most important benefit of standing.

Standers come in a wide selection of models; the most appropriate depends on the abilities and goals of the individual child. Prone standers support the user from the front; supine standers provide support from the back; and vertical or upright standers support the user in an upright position. A few models can support a child in all three positions. "Dynamic" standers can help a user rise to a standing position from a seated or prone position.

Some standers are stationary. Others have small casters or wheels, so the equipment may be moved easily. Standers may be designed to be propelled by the user—manually or by electric motor—or pushed. All standers come with pads or straps for appropriate positioning. Some children will require additional positioning aids as well.

Defining goals

A team that includes parents and professionals can determine whether standing equipment will be helpful. Professionals on the team usually include occupational and physical therapists, rehabilitation technology suppliers ("dealers") and, sometimes, rehabilitation engineers and a physician.

Many professionals suggest that parents discuss goals—their own and their child's—before concerning themselves with specific pieces of equipment. Focusing on specific activities a child wants to enjoy but cannot now do independently can lead to team discussions of the steps necessary to reach specific goals, the length of time required and the specific types of therapy and equipment, such as standers, that may be helpful.

Parents and professionals also need to discuss how specific equipment will be used, when and where it will be used and which team and/or family members will be involved in its use. Ideally, the equipment can be integrated into the normal activities of a child's everyday life.

It is also important to think about a stander's long-term use. Should it be considered a transitional tool, meant to help the child develop a specific skill before being adjusted or removed; or is it intended to become a relatively permanent positioning tool?

Being an informed consumer

Parents and children need the opportunity to try out standers before deciding on a specific purchase. Parents can ask therapists or dealers to demonstrate different types of standers. These demonstrations can illustrate the stability and portability of different standers—remember to ask about the adequacy of braking systems when the stander is on casters or wheels. Professionals can show parents how the stander works, how to help a child into and out of the stander and how to transport it from room to room or from home to school. Parents can also ask to be put them in touch with other parents using similar equipment.

Some standers can be adjusted for changes in physical size and ability. While adjustability may be an important consideration for some children, the stander needs to be safe, comfortable and attractive at the time the child begins using it—it is not equipment to "grow into."

The clinical team, and especially the rehabilitation technology supplier, can work with parents regarding payment for the stander. Health insurance policy restrictions may need to be factored into the decision process. Parent consumers also need to consider equipment maintenance; it's important to ask about warranty and service agreements, the ease of getting repairs, costs of repairs and insurance coverage for such expenses.

Linda Hillyer is a Boston-based freelance writer.

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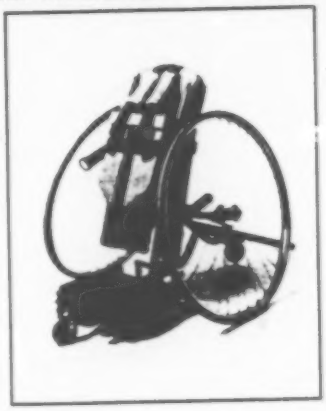

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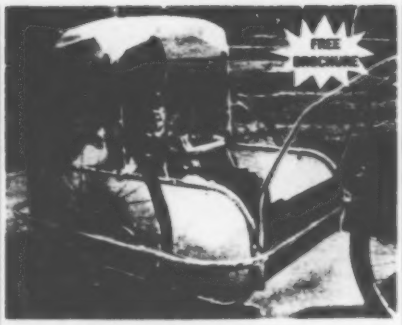

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Circle #18

ASK THE DOCTOR

Planning Air Travel

by David Hirsch, M.D.

Q Our four-year-old son has cerebral palsy and chronic lung disease from complications of bronchopulmonary dysplasia. He also has asthma. He uses a manual wheelchair. Because of his lung disease, he often requires oxygen, especially when he gets bad colds or at higher altitudes. Because of his asthma, he frequently requires inhalation treatments using a small volume nebulizer (SVN).

We are planning our first family vacation in five years. We will be flying on a commercial airline. We want to do as much advance planning as possible. Do you have any suggestions to make air travel easier?

A You are absolutely correct that advance planning is very important when traveling with a child (or adult) who has special needs. Not only should you make advance arrangements with the airline, but also with your hotel and the facilities you will be visiting.

I would recommend anticipating that your son will require oxygen and the use of his SVN machine during the flight. This type of planning will ensure that his equipment will be available if needed. The airline will not allow you to use your own oxygen, but most will make oxygen available to your son with a doctor's note or a phone authorization describing the flow rate (liters per minute) and method of delivery (for example, nasal prongs, tracheostomy collar or mask).

It should not be a problem to carry your son's SVN machine on the plane, but you will want to make sure it is on the "approved list" of equipment that can be operated on the airline. You will need to arrange for an electrical hookup unless the SVN is battery-powered.

In case of travel delays or difficulty getting your luggage immediately, you will want to bring some additional medications (such as nebulizer solutions) in your carry-on luggage. Your son's own oxygen and equipment can be transported as cargo as long as it meets packaging and labeling requirements available from the airline. These requirements are very strict because of safety concerns. For example, oxygen generators that produce heat would probably not be allowed.

Your son's doctor can also arrange for a medical supply service to provide oxygen while you are at your destination. As long as the oxygen is prescribed by a physician, most insurance carriers will cover its cost, even in a different state. It is unlikely, however, that these costs would be covered in a foreign country. You should check with your son's insurance carrier to find out how coverage will be handled in his case.

The April 1996 issue includes many helpful articles on the topic of travel, including airline travel with a wheelchair. You may also wish to contact a travel agent who has experience planning trips for individuals with disabilities or special health care needs. With careful planning, your family should encounter no barriers to a wonderful time! **EP**

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

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WHAT'S HAPPENING

Raising Down Syndrome Awareness

Guiding Light, a daytime television drama, has inaugurated a groundbreaking storyline involving Down syndrome. Although other television series have included regular characters with Down syndrome or mental retardation, *Guiding Light* may be the first to deal with the difficult issue of prenatal diagnosis. Television parents Holly Lindsey-Reade (played by Maureen Garrett) and Fletcher Reade (played by Jay Hammer) received the diagnosis of Down syndrome after Holly underwent amniocentesis in December 1995. The couple's decision to continue with the pregnancy also represents a long-term commitment on the part of the show's producers, who plan to cast a series of children with Down syndrome to play the Reade child at different ages.

Above, Jacqueline Falchier with her television mother, Maureen Garrett; below, on the show's set with real-life mom Rosetta.

The first young actress to play the role of Meg Reade, beginning with her birth on April 8, 1996, is Jacqueline Falchier of Maplewood, New Jersey. Jacqueline was cast with the help of the National Down Syndrome Society (NDSS, 666 Broadway, New York, NY 10012-2317; 800/221-4602), which has been working closely with the show's writers. NDSS hopes the storyline will raise awareness about Down syndrome. NDSS executive director Myra E. Madnick calls Jacqueline "the youngest advocate we have." "[She] doesn't realize it yet," says Madnick, "but she's going to help teach millions of soap opera fans that children with Down syndrome have many wonderful abilities and talents. She'll be instrumental in changing attitudes and increasing acceptance."

In fact, one of the first beneficiaries of the storyline has been Jacqueline's mother, Rosetta Falchier. "Early on, I was just so focused on Jackie's Down syndrome that I had trouble seeing her as an individual," Falchier explains. "*Guiding Light* and NDSS have helped me raise my expectations. I now recognize that Jackie has so much potential for a bright future."

1997 Resource Guide

We are now compiling information for the EXCEPTIONAL PARENT 1997 Resource Guide. This process begins with correcting errors found in the 1996 edition. Please let us know—in writing, by August 15—of any errors you have found; we'd also like to hear about organizations that should have been included but were not. Contact: Resource Guide Update, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742, fax.

Down Syndrome Amongst Us is a new magazine published by a young, orthodox Jewish mother of a six-year-old son with Down syndrome. The magazine addresses the medical, educational, psychological, emotional and religious needs of Jewish individuals with Down syndrome, as well as the community's response to and acceptance of children and adults with Down syndrome. *Down Syndrome Amongst Us* is available in major Judaica stores worldwide. For more information, contact editor Sarah Sander at (718) 834-2055; (718) 834-5255, fax.

FUNNY AS A CRUTCH by Frank Bernard, Jr.

WHAT HAPPENED TO YOU?
WELL, I'LL TELL YOU.
C'MON, LET'S GO. HE DOESN'T WANT TO BE BOTHERED.
YOU'RE RIGHT. I DON'T. SO TO AVOID THAT, HOW ABOUT LETTING ME EXPLAIN MY DISABILITY TO HIM.

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Children's Health Notes

Brave New Partnerships:
Children & Youth with Disabilities, Families and Managed Care

Headlines declare it: Managed care is the future of health care delivery in this country. And there's no end of controversy around it—especially when so many children with disabilities are being moved from fee-for-service to managed care. Still, little is known about how children with chronic illness or disability do in managed care.

That's why HealthPartners-Group Health (the largest health maintenance organization in the Twin Cities), the Center for Children with Chronic Illness and Disability (C3ID), and the PACER Center (a parent training and advocacy center) set out to study children with disabilities already enrolled in managed care.

C3ID, HealthPartners, and PACER completed:

- *An in-depth interview with 35 parents of children with chronic conditions enrolled in HealthPartners;*
- *A financial analysis of the 410 children within eight categories of chronic conditions; and*
- *A survey of HealthPartners physicians to understand their perspective of providing services to young people with disabilities and chronic illnesses.*

In addition, they convened two community working groups—a Parent Advisory Council and a Community Advisory Council.

The outcome is mixed. On the one hand, families are doing well; on the other, they are relying on a hodgepodge of financing that may be dramatically reduced in the near future. Families really need access to more information. They need more interagency coordination, and more preventive mental health services if they are to thrive.

Most families are satisfied with their child's pediatrician and overall health care. They appreciate the convenience of having a primary care clinic as the site where most medical care occurs. HealthPartners' system promotes the strong central role of physician as medical care coordinator.

HealthPartners does not cover all expenses incurred by the family. Costs are currently being underwritten by a combination of HealthPartners dollars, public program dollars, and the public educational system.

The parent survey shows that schools cover between 60-80 percent of physical therapy, occupational therapy, and speech/language services. The annual cost for these 410 children within

Turn to page 62

THE SOURCE

The material presented here is based on a report to The Robert Wood Johnson Foundation (Grant 026523) by researchers: Robert Wm. Blum, M.D., Ph.D.; W. Brooks Donald, M.D., M.P.H.; Anne Kelly, M.D., M.P.H.; Andrew Nelson, M.P.H.; Ceci Shapland, R.N.; and Barb Staub, M.D. from HealthPartners, the Center for Children with Chronic Illness and Disability and PACER Center. Complete findings of a planning grant to establish an integrated service system in an HMO for children with chronic illness and disease will be available later this summer. For more information, contact Peggy Mann Rinehart, C3ID, Box 721 UMHC, 420 Delaware St. S.E., Minneapolis, MN 55455. The project was also sponsored, in part, through the National Institute on Disability and Rehabilitation Research Grant H133B40019.

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BRAVE NEW PARTNERSHIPS
From page 61

HealthPartners is between $400,000 and $800,000. That's two to four times more than the amount HealthPartners paid for these services over the same period.

HealthPartners (and most insurance providers) provide coverage based on adult, acute, rehabilitative therapies rather than the habilitative needs of children. This limits coverage of therapies children need.

Eighty-eight percent of families say they need help with stress management. Of the families reporting this need, two-thirds report that they have not been able to find needed help. Only two families reported using mental health services, and only two more indicated any problem in accessing needed mental health services. Clearly, mental health support services are needed and the present system of mental health services is inadequate to meet that need.

All agree that case management is generally done for the benefit of the agency rather than the family. Currently, most non-medical case management occurs through the schools, and a common response was that the school case load was far too heavy for careful follow-through. Families seemed most satisfied when the case manager knew their child well and was a perceived advocate. Too many case managers and frequent changes in them were perceived problems.

Clearly, further research is needed in order to develop and test criteria needed to assess the quality of children's health in general and those elements which will result in quality care for children with chronic conditions within managed care environments. We do not know the impact such service systems have on access, utilization of services, out-of-pocket costs, family distress, and coordination of care. Proponents argue that managed care is the optimal setting in which to develop integrated, coordinated, community-based and family-centered services; but whether the reality will match the theory is, so far, untested.

Where Do the $$$ Go?

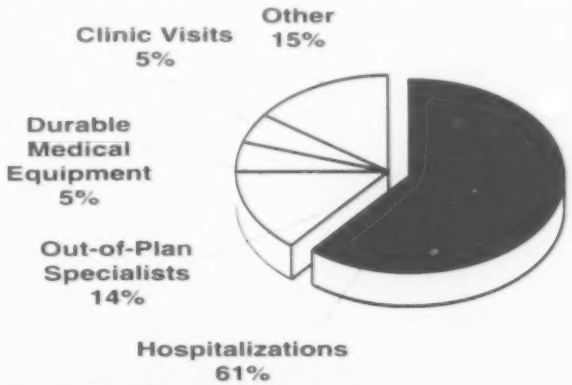
The annual cost of HealthPartners care to 410 children with chronic illness or disability was just over $6.2 million. Almost two-thirds, or $4.15 million, was spent on hospitalization.

The 25 "most expensive" children accrued hospital costs ranging from $15,633 to $770,060. Clearly, hospitalization is the single most expensive service provided to children and their families. Reducing hospitalization would save the system thousands of dollars.

It appears that children and youth who received more outpatient services spend less time in the hospital. For example, diabetes had a disproportionately low total cost and low costs for hospitalization. But diabetes also had the highest average cost for HealthPartners clinic expenses. Perhaps intensive outpatient monitoring helped keep hospitalization rates low.

However, some disabilities and chronic illnesses, like cystic fibrosis and heart disease, have a high rate of hospitalization. They are the most expensive conditions for HealthPartners to manage. Other conditions such as autism and trisomy 21 (also known as Down syndrome) are less expensive for HealthPartners. Children with such conditions often require specialized services typically provided through the schools and in-home support.

There is still a debate about who should fund health-related services. The HealthPartners system limits outpatient services and yet it may be that when clinical, educational and home management occurs, hospitalization as the single greatest expense to the system decreases.



The Center for Children with Chronic Illness and Disability is a research and training center dedicated to the study and promotion of the psychological and social well-being of children with chronic conditions and their families.

The mission of NCYD is to improve the health and social functioning of youth with disabilities by technical assistance and consultation, disseminating information, and increasing coordination of services between the health care system and others.

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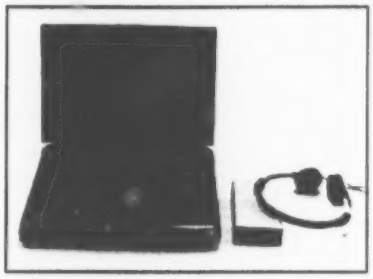

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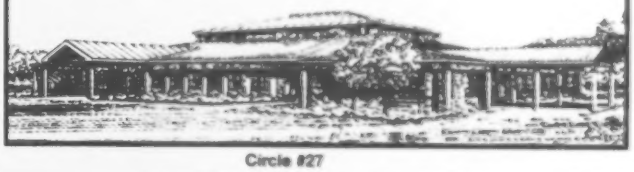

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Circle #46

Non-Prescription Medications

by Richard Epstein

Q I am a family counselor working in New York City. One of my teenaged clients has a rare mitochondrial disorder that has resulted in hearing and vision impairments, fine and gross motor difficulties, diabetes, and Fanconi syndrome (a kidney disorder leading to excessive excretion of bicarbonate, glucose, amino acids, phosphates, potassium and calcium).

Her family is overwhelmed with medical bills. Their insurance pays for only part of her hospitalizations, ongoing treatment and doctor visits. It does not cover her medications, which cost over $300 each month.

The family has written to their insurance company and to government officials without success. They have applied for SSI for her, but the application was rejected. They've applied for a Medicaid waiver, but it has been tentatively denied as well. Can you provide some advice?

A Judging by the doctors' comments accompanying your letter, part of the problem seems to be that many of the medications your client requires are non-prescription. These include riboflavin, sodium bicarbonate, potassium supplements, vitamin C, vitamin D and magnesium oxide.

Health insurance policies do not usually cover non-prescription medications like these because they are considered dietary supplements. But, since these medications are an essential part of your client's medical treatment, they clearly perform a far more important function in her case. Unfortunately, based on the materials accompanying your letter, the family's insurance policy appears to have been provided through an employee welfare fund. If so, it would be regulated under ERISA, a federal law, not under New York state regulations (see "Self-Funded Insurance Plans," July 1995). That means state regulations regarding special formulas and other supplemental foods for children with specific disabilities would not apply.

The family should immediately file appeals of the denied Medicaid and SSI applications. The National Legal Aid and Defense Association (202/452-0620, voice; 202/872-1031, fax) or the local Bar Association can offer advice on filing appeals. In addition, a free factsheet, *Appealing a Social Security Disability Benefits Decision*, is available by sending a SASE to The Arc, 500 E. Border St., S-300, Arlington, TX 76010.

In the meantime, the family may find it worthwhile to explore other possibilities. For example, the Disabled Children's Relief Fund offers grants to help families nationwide meet the cost of medical equipment or services for children with disabilities, particularly when such items are not covered by health insurance. Contact the Disabled Children's Relief Fund, 402 Pennsylvania Ave., Freeport, NY 11520; (516) 377-1605, voice; (516) 377-3978, fax.

Your client's local school system may also be able to help. If she requires a hearing aid, for example, you may be able to show that it is directly related to her educational needs. In that case, the school district may be willing to have it listed on her IEP, which would require them to pay for it.

Because your client lives in New York, her family may also be able to take advantage of Child Health Plus, a state-subsidized insurance program for children with disabilities under the age of 16. The program has extremely low premiums but only provides coverage for outpatient treatment. If a child is hospitalized, the family is expected to apply for Medicaid on an emergency basis. In addition to rules regarding income levels, the family must apply before the child reaches age 15. For information, call Child Health Plus at (800) 698-4543. (For information on similar programs in other states, contact your state's Department of Health.)

Community service organizations often offer support to children with disabilities. Although that usually involves the purchase of items such as wheelchair lifts, vans or computers, some may consider helping with purchase of essential medications as well.

Two other organizations may offer additional information: United Mitochondrial Disease Foundation, P.O. Box 1151, Monroeville, PA 15146-1151; (412) 856-1297 (voice/fax); and the Mitochondrial Disorders Foundation of America, 5100-1B Clayton Rd., Ste. 187, Concord, CA 94521; (510) 798-8798 (voice/fax).

Finally, the family should consider contacting an attorney to determine whether legal issues are involved, including rights under ERISA and the Americans with Disabilities Act. In New York City, the family can contact New York Lawyers for the Public Interest (30 West 21 St., 9th Fl., New York, NY 10010; 212/727-2270, voice; 212/727-2997, TTY; 212/727-2996, fax). **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at Exceptional Parent, *209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742 (fax).*

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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Auditory Scanning

by Howard Shane

Q My five-year-old son has severe cerebral palsy, a seizure disorder and gastroesophageal reflux. He is blind and has the motor skills of a three-month-old. His intellectual ability is estimated to be at the 24-month-old level. His only form of communication is to smile for "yes," to scowl for "no," or to cry.

We are trying to find an appropriate augmentative communication device for him. At school he is using a large, hand-activated switch to operate toys and appliances, but we are looking for a device that will offer him choices and allow him to make selections.

A The quest for an augmentative and alternative communication (AAC) device is a reasonable pursuit with the idea of "making choices" as a reasonable goal. In fact, your son's teachers and therapists may share this goal. Through switch training at school, they are probably attempting to teach your son about cause-and-effect relationships. Developing an understanding of cause and effect, in part through accurate and reliable switch control, can lead to achieving the larger goal of accessing and using an AAC device.

In this regular department, questions from readers are answered by staff members of the Communications Enhancement Center at Children's Hospital in Boston. The clinic is directed by Howard Shane, Ph.D., a speech and language pathologist and a member of the EXCEPTIONAL PARENT *Editorial Advisory Board.*

Since questions are answered without an interdisciplinary assessment, parents need to review any suggestions with appropriate professionals. Specific products are mentioned only to illustrate suggestions, not as endorsements.

Send questions to **Technology.** EXCEPTIONAL PARENT, *209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

A likely approach

Rather than recommending a specific AAC device, I would prefer to suggest a likely AAC approach. This can be done by focusing on the characteristics or features an AAC device requires to meet your son's needs. In this case, your son's visual and motor abilities will have a compelling influence on the selection of an appropriate AAC approach. Because he is blind and has a significant motor disability, he may benefit from an approach known as auditory scanning.

With auditory scanning, the communicator prepares a message by choosing from a menu—presented in the form of letters, words or categories—spoken aloud, in sequence, by the device. The communicator chooses a desired item by activating a switch at the correct time. (Parents and professionals can choose from a large assortment of commercially available switches.) For example, a child who wants an ice cream cone might first listen to a computer voice delivering the following choices: 1) I want to listen to music; 2) I want to go for a ride in a car; 3) I want to turn on the fan; and 4) I want an ice cream cone. The child would activate his switch when the final choice—"I want an ice cream cone"—is spoken. His action would cause that sentence to be repeated.

Once the child has become proficient at making choices this way, the information could be presented in categories (for example, music, transportation, appliances and food). Activating the switch when the word "food" is spoken would lead to the presentation of a series of food choices (for example, meat, vegetables, ice cream, fruit). Eventually, choices could be presented through earphones for private review.

Auditory scanning proficiency is usually attained only with intensive instruction and practice over several months, even years. This is because this communication method requires competence in several areas. Proficient users of this type of AAC must have the ability to comprehend computer-generated speech, to relate a spoken choice to a personal desire, to operate a switch, to coordinate switch operation with the presentation of a spoken statement and, in the case of more advanced types of auditory scanning, to navigate through a menu of choices.

Your son is already working toward becoming proficent in the control of a switch. Once this is achieved, he can begin learning to operate the switch in response to a spoken message containing information he wishes to select. In the earliest stages of associating switch activation with a spoken message, we sometimes suggest that the switch be connected to a buzzer or bell that will sound when a desired item is mentioned and the switch is activated. This skill can be practiced with a person speaking the choices or with a tape recording.

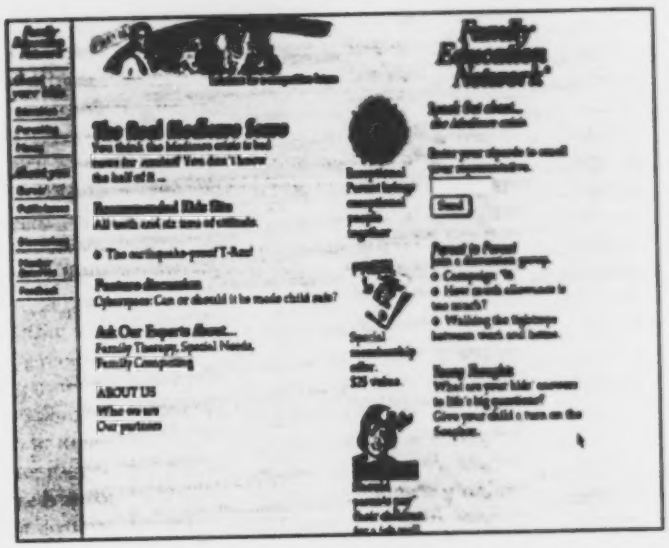
Once your son develops the necessary skills to use auditory scanning, you'll have a number of devices from which to choose. Your options will also include AAC software that can be used with a personal computer. The sidebar contains a non-exhaustive list of options. However, it would be impossible for me to recommend one over another for your son; each has a unique set of features that must be considered in selecting the specific technology most suited for a specific individual. **EP**

Family Education Network

What's new at http://families.com

by Ellen Goldberg

As we move ever closer to September 10—the official launch date for the Family Education Network (FEN) at http://families.com—the site continues to grow rapidly. We'd like to share all of what's happening on FEN, but there's so much to talk about, we couldn't possibly touch on it all. Instead, we'll talk about specific areas FEN offers you.



A place to connect

We want to hear from you. FEN's Special Needs area is your forum, your place to get answers and to share your experiences. As we continue to develop an area rich in content, we'll focus on such topics as education, family issues, and living in the community—with lots more to come.

The Internet has hundreds of resources already available. We'll show you where they are and how to find more of them. We'll also bring more people with common interests together, so they can learn from each other. On FEN, you'll read about the newest research being done in hospitals and the latest findings regarding learning disabilities. We'll also have special reports, such as live on-line interviews with athletes with disabilities. Above all, we'll try to help make your lives a little easier.

Do you want answers?

One of FEN's newest features is Questions & Answers. In Questions & Answers, top specialists answer your questions on all topics. By simply typing in a keyword, you'll be able to find information about your area of interest, or you can ask the expert a new question.

In the fall, we plan to have live on-line events where you'll get to talk with doctors and other professionals about questions and problems. Look for a calendar of events in future issues of EXCEPTIONAL PARENT, as well as on FEN.

Speak up

FEN wants to know about you! About 10 percent of subscribers will find a survey in the back of this magazine. This is your chance to tell us about yourself, your computing habits and what you're looking for from FEN's Special Needs area. We're always eager to hear from EXCEPTIONAL PARENT readers, so feel free to send an e-mail message at any time to elleng@families.com with your ideas, questions, or concerns.

Speak out

Every week, FEN features a specific issue to debate. Recently, discussions have centered on such issues as national service (AmeriCorps), the entitlement crisis and the potential bankruptcy of Medicare. FEN publishes an article outlining the week's issue, the history behind the story and the opposing viewpoints. From there, you can participate in moderated discussions where everybody can share opinions, and (hopefully) come to a better understanding of the issue at hand.

Those of you who would like to become more involved politically—especially when it comes to issues that concern your children—can use the Zipper tool. Simply type in your zip code, and the Zipper determines your elected officials in the U.S. Congress. If they use e-mail, you can contact them electronically from within FEN; otherwise, the Zipper tells you how to get in touch with them by more traditional means. Soon, you'll be able to use this method to contact your governor and the head of the education department in your state as well.

Searching for others?

EXCEPTIONAL PARENT's on-line Search and Respond area is up and running! To create a new Search, click on the "Submit a Search" button and write your question. You request is mailed to a moderator, who makes sure that it is posted within a week. Submitting a response is just as easy; click on the "Submit a Response" button and enter your reply. Every day, FEN users are adding more Searches and Responses, so be sure to check the area frequently.

Ellen Goldberg is a producer at the Family Education Network in Boston, Massachusetts.

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The Challenge of Family Involvement

by Maureen H. Greer

In March 1978, my son, Adam, was born eight weeks prematurely and diagnosed with respiratory distress syndrome. Though critically ill, he recovered completely and became a typically developing toddler. Sixteen months later, my daughter, Sarah, was also born eight weeks prematurely. Sarah spent most of her early life in and out of hospitals and therapy programs. The births of my children changed the direction and focus of my life. In the 18 years since, I have been dealing with the issue of family involvement at local, state and national levels.

Never one to do anything by half, I began by leading parent meetings, teaching health care professionals, training parents to provide peer support and maintaining a hotline for parents of high-risk newborns. I worked with other parents and professionals who believed firmly in the value of family involvement.

In the early years, I frequently felt the frustration of being the token parent on many committees and task forces. While my fellow members would discuss the importance of family involvement, they failed to achieve that goal. They said I was an exception.

A flexible definition

Today, many people realize how important it is to listen to families and get them involved in the areas of health care, social services and education. But as a parent and the early intervention coordinator for the state of Indiana, I know this is still a challenge for professionals and organization leaders.

Family involvement means incorporating family perspectives in the process of planning and decision-making in policy and program development, implementation and evaluation. Organizations need to define their goals and outline the specific roles that families can fill in achieving those goals. Clearly defined roles, responsibilities and expectations will assure successful collaborations and allow parents to feel like useful—not token—participants.

With their busy schedules, many families are hard-pressed for time. If making a long-term commitment is difficult, families can participate in one-time activities. Parents can fill out surveys, attend coffee hours, serve as co-trainers or mentors or assume paid staff positions—the range of options is limitless.

If professionals take the time to understand why families decide to get involved—or not to get involved—they will be better-equipped to reach out and recruit families. Families get involved for three important reasons:

- *They think they can make a difference:* Before devoting their time and energy to an activity, families need to know that something might happen as a result of their efforts. They need to be respected and recognized for their involvement, not patronized.
- *They have formed meaningful relationships:* If families have positive relationships with other people who are involved in a particular activity or organization, they are more likely to participate themselves. Families often need support from someone they already know to face the challenge of building new relationships.
- *The issues they are dealing with have meaning for them:* Involvement will only be successful if families believe that their investment of time and energy will have positive impact on their own lives. If they can't see benefits for themselves or other, similar families, their involvement probably will not continue.

The Greer family: (standing, left to right) Sarah, 16, Amy, 24, Adam, 18, and Kelly, 21; (seated) Maureen and Tom.

Family involvement requires new behaviors, new attitudes and new skills on the part of professionals *and* parents. It is hard work. Most people have not been trained in communication skills, team process or conflict management. Providing this training for both parents and professionals will make the investment of time and energy worthwhile. If we believe that family involvement is beneficial to everyone—children, parents and professionals—we must be willing to work at it. All participants must believe that the benefits outweigh the costs. **EP**

Maureen H. Greer is the assistant deputy director of the Bureau of Child Development, Indiana Family and Social Services Administration, and the treasurer of the National Perinatal Association (NPA, 3500 E. Fletcher Ave., Ste. 209, Tampa, FL 33613-4712; 813/971-1008; 813/971-9306, fax). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time-of-birth) health issues from preconception through infancy. She has also served as president of Parent Care, an international organization committed to improving outcomes for high risk newborns. Ms. Greer lives in Indianapolis, Indiana.

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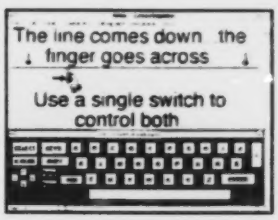

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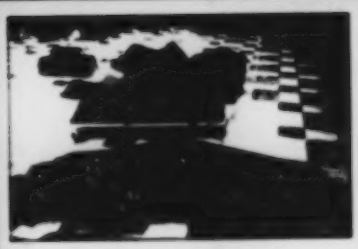

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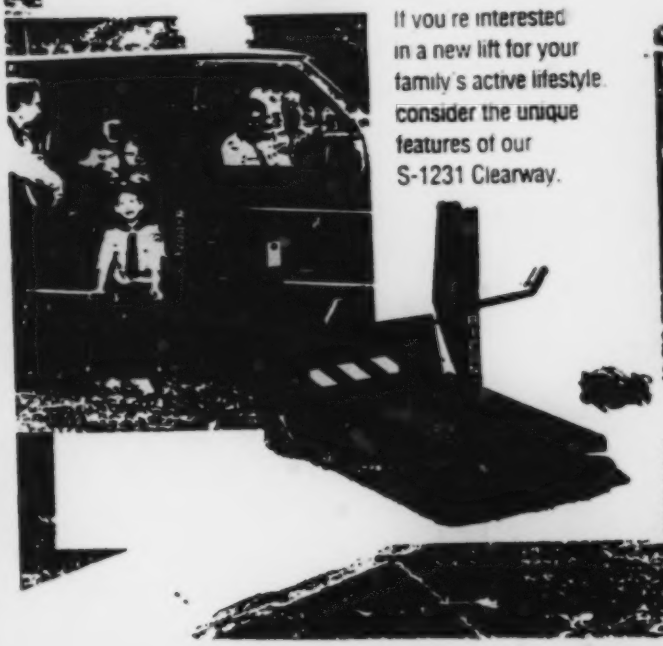

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- *How far does it extend into the vehicle?*
- *Does it become an obstacle to easy transfer or swiveling?*

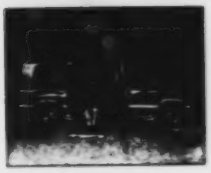

Photo courtesy of Braun Corporation. See ad on page 7.

If an individual will be driving or riding in a wheelchair, it is also important to consider the van's height. Measure from the roof to the floor, and then determine the seated height—from the floor to the top of the head—of the individual seated in a wheelchair. There are a few options for adding head space.

If you plan to use a wheelchair lift, you need a full-size van with a long wheel base, or an extended body. This will give the wheelchair user ample room to maneuver when entering and exiting.

Don't forget to measure the doors as well. If the wheelchair user cannot bend his or her head forward to fit through the standard doors, you should ask your dealer about raised doors. If you don't include the raised doors with the initial conversion, you may later face the unnecessary expense of removing the van's interior to install a new van top compatible with these doors.

Minivans

Photo courtesy of Vantage Mini Vans. See ad on inside back cover.

Some of the considerations that go into the purchase of a full-size van also apply to minivan purchases. These considerations include head room and door height. Most adapted minivans on the market have a floor-lowering device with a side or rear ramp. However, choosing a rear-entry ramp means losing rear and center seats, which further limits the number of passengers it can carry.

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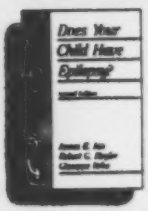

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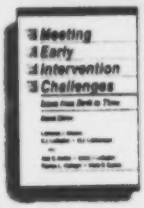

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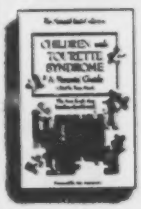

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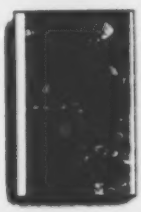

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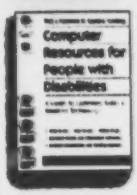

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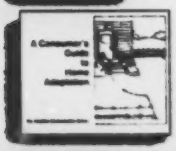

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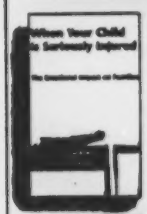

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CHILDREN'S PAGE

by Megan Consbruck

From left, Megan, 6, and Brittany, 4, enjoy the company of Big Bird and baby brother Justin.

Mom's Turn:

Last year, Megan sent this article to EXCEPTIONAL PARENT *all by herself, having gotten into our family photo album without permission, taken some photographs and mailed them off! It was too late for me to catch the mailman to have reprints made first.*

Brittany was diagnosed with Rett syndrome when Megan was only four, and although I don't think Megan understood why Mom was so sad, she knew something wasn't right. Megan understands a lot more now and is always more than willing to explain to others what is different about her sister. I think she does a very good job at it—in Megan's own words, "Brittany is just one very special girl."

Megan enjoys taking her sister for walks, reading books to her and helping with her physical therapy. Brittany's favorite pastime is watching music videos, and Megan likes watching them with her.

—Shanna Consbruck

Megan and Brittany meet one of the Teenage Mutant Ninja Turtles during a 1993 trip to Walt Disney World.

I LOVE BEING WITH MY SISSTER!

I love being with my sisster because she is fun to be with.She likes Barney a lot so we watch the tapes with her all the time. And once we were at a store and Barney was there so we got our picture taken with Barney.Brittany is Handycapped but we still love her more than anything in the world.Brittany got a nick name and it is B Brittany lookes at us when we say B . Brittany can not talk,walk,or eat therw her mouth.She has a button that she eats therw.It is in her stomach.

Megan Consbruck, now 10, will enter fifth grade at St. Michael's School in September. She lives in Hastings, Nebraska, with her parents, Shanna and Dan, sister Brittany, 8, and brother Justin, 4. Megan enjoys dancing, swimming and riding her bike. Her other hobbies include crafts and writing.

Brittany has Rett syndrome, a genetic disorder that occurs only in females and causes mental retardation, repetitive hand gestures and a loss of purposeful hand skills. Brittany attends a developmental training program at Abraham Lincoln School in Hastings, where she enjoys music and being with friends.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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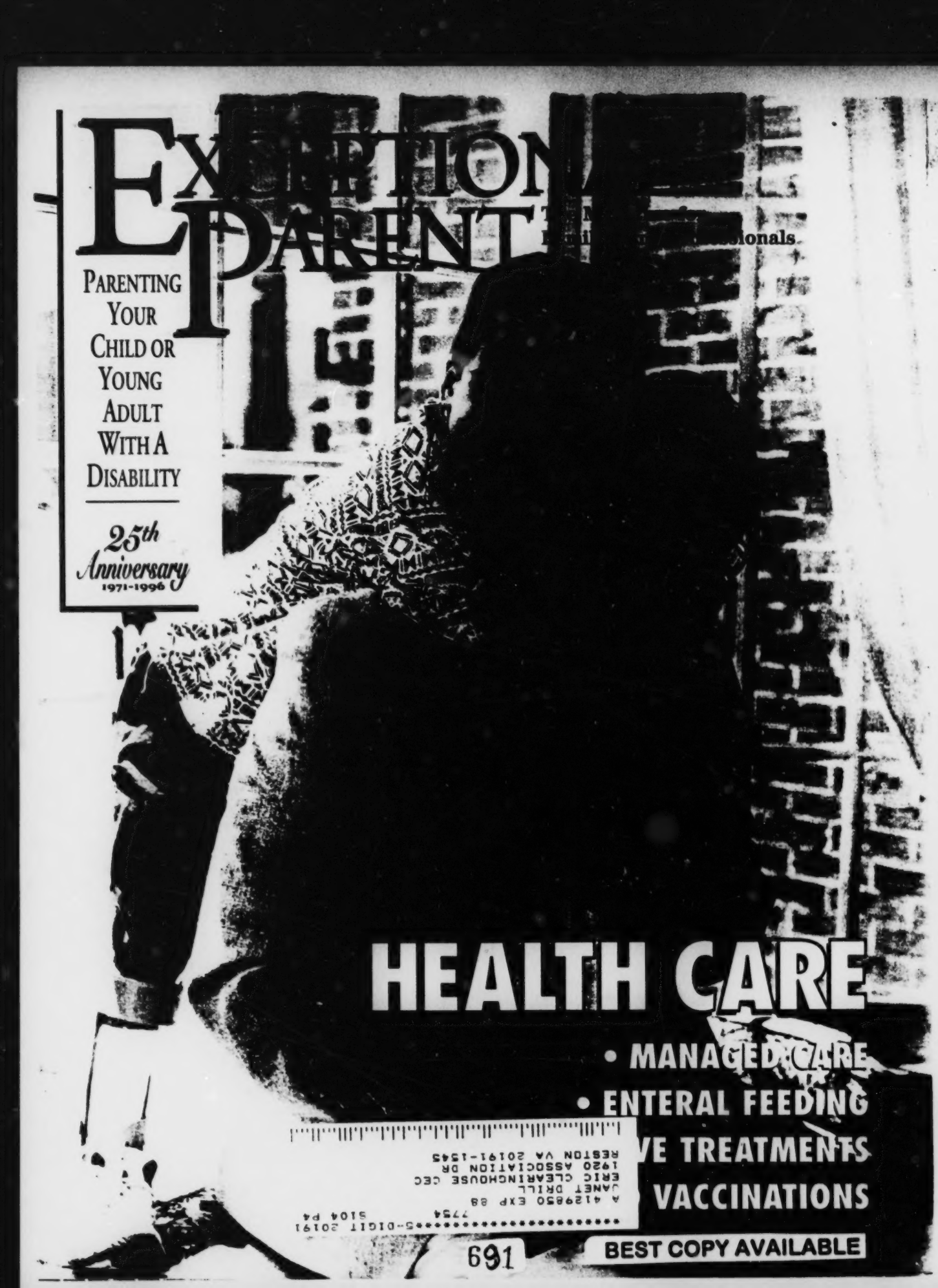

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Cover: John Salamone and his son, David, 6, share an affectionate moment in their Oakton, Virginia home. David Salamone contracted polio as a baby from the oral vaccine that was supposed to protect him from the virus.

Unbeknownst to his parents, David was born with a genetic disorder known as Brutons agammaglobulinemia, which left him with only a limited immune system and made him vulnerable to the live polio vaccine.

John Salamone has since worked to promote awareness of the potential dangers of the live vaccine. (See "Telling David's Story," page 23.)

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BPA

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EDITOR'S DESK

You deserve a break!

We are eagerly anticipating our special 25th Anniversary Celebration, Forum '96, at the Anaheim Hilton and Towers in Anaheim, California, beginning on Thursday, October 17, 1996, and continuing through Sunday, October 20. The complete program is contained in this issue. While the program includes fine speakers, interesting panel discussions, wonderful workshops and fascinating, interactive product exhibits, the most important component is fun—fun making new friends and enjoying special events and nearby entertainment facilities. You can still decide to put aside all the demands of everyday life and make plans to join us. Every reader of EXCEPTIONAL PARENT I've ever met not only *deserves* a break, but *needs* one. And so do we!

STANLEY D. KLEIN, PH.D.

Health care

We were pleased that so many readers took the time to write about their positive health care experiences. Such stories give hope that parents and health care professionals can collaborate in mutually beneficial ways—even within the uncertainties of our ever-changing health care system. These are living examples of the value of family-centered care, as illustrated in the research we reported in the July issue.

But as managed care makes greater inroads, we also hear the horror stories. That is why we are pleased to share "Managed Care," a vision for family-centered managed care that readers can use to advocate for the kind of care their families deserve.

Media attacks

Recent attacks on special education programs have been seen by millions on television (*60 Minutes*) and in newspapers (*USA Today*). Sadly, these attacks gave only sensationalized examples of high costs without addressing the value of these programs' successful outcomes. They could have found great examples in the young Role Models featured in our June issue. These young people, and thousands like them, are already "paying back" their communities. And they are well on their way to being working adults who will pay taxes for many years to come. Before special education, this would not have been true—too many adults with disabilities were supported by public funds at home or in inhumane institutions.

Those media sensationalizers also fail to calculate the taxes paid by parents who are able to work because they are not providing around-the-clock care for their children as did previous generations.

But most of all, those reporters did not have the courage or understanding to address a fundamental problem in every community—the way that public education is funded. Parents advocating for music or sports programs clash with their neighbors advocating for special education because public education is almost always funded primarily by local property taxes. Although the Federal government long ago promised to fund a far greater proportion of special education services than has ever been delivered, it is also true that all of us pay all kinds of taxes—some hidden, some not—that support all kinds of programs—some educational, some not. It is sad that some parents have to "beat out" others so that some children can have the appropriate education every child deserves. In this election year, we need to advocate for our leaders to address the big picture and explore ways to do what is right in both education and health care.

Thanks

Thanks to the readers who received a survey with the July issue and completed it. For others, I hope this will be a reminder.

Frank L. Brunetti, who has contributed a fine series of articles answering questions about financial and estate planning, is unable to continue in this role. Fortunately, Theresa Varnet, parent, attorney and well-known speaker, will take Frank's place.

Thanks to all the readers who have contacted the March of Dimes as a result of articles and letters we have published. They are listening and have accepted our invitation to respond in these pages in September.

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EXCEPTIONAL PARENT

Parenting Your Child of Young Adult With a Disability

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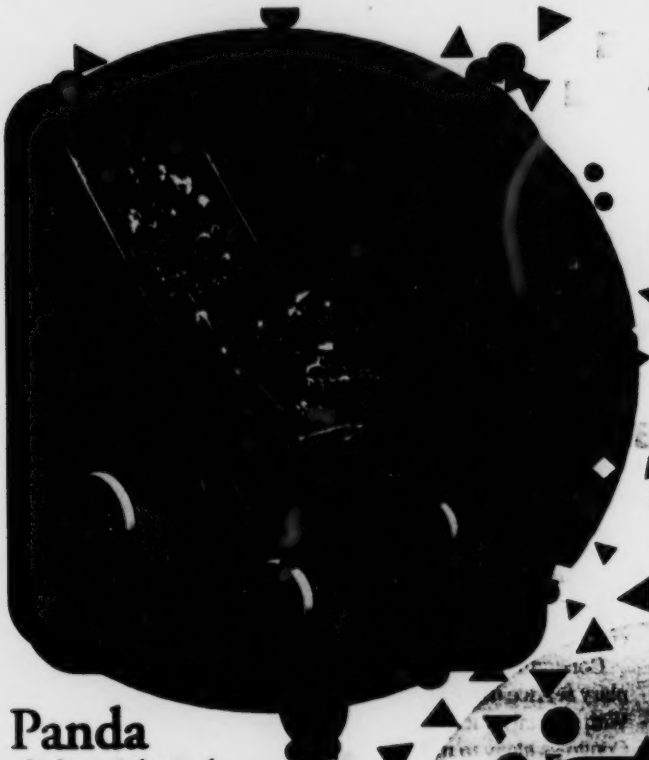

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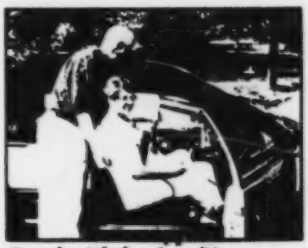

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LETTERS

Correction

I appreciate your kindness in publishing the extensive interview with me in EXCEPTIONAL PARENT's 25th Anniversary issue ("The Golden Age of Special Education," June 1996). However, an editing change makes me appear to be claiming P.L. 94-142 as *my* accomplishment. That is not the case; I was one part of a team effort involving many people. In answer to the question, "What do you consider your major accomplishments?" I pointed out that many people were involved in all the legislative and policy changes with which I was associated. When I later returned to that question I wrote, "another major accomplishment was..." Unfortunately, in editing, that statement was changed to "*my* other major accomplishment..." This change has me incorrectly appearing to be taking credit for the joint efforts of Sen. Harrison Williams; Rep. John Brademas; Lisa Walker and Jack Duncan, who were the key congressional staffers; Fred Weintraub of the Council for Exceptional Children, who was central to the Act's development, and many others. I was happy to be part of that group that worked together over more than three years to help shape the legislation.

I hope this letter will ease the concerns of any readers correctly amazed and repelled at the reference to "my."

Congratulations to EXCEPTIONAL PARENT on 25 years of exemplary service to children with disabilities and their families. With special education funding under attack, and the current Congress likely to make changes that will weaken what we now call the IDEA (Individuals with Disabilities Education Act), your efforts and those of your readers are critical to protecting the hard-won educational programs for all children with disabilities. If we suffer a temporary setback, we can recall the words of William Faulkner when he accepted the Nobel Prize. Speaking of the inner spirit of mankind at its best, he said, "we will not only endure, we will prevail."

Edwin W. Martin, Jr., Florida
Former Assistant Secretary for Special Education and Rehabilitative Services

Why Was Your Baby Born Early?

As the parents of a six-year-old son with spina bifida, we can completely relate to the outrage and bewilderment Teresa Wolding expressed in "So...Why was *Your* Baby Born Early?" (March, 1996) about the March of Dimes public service advertisements (PSA's). Several years ago, we wrote to the March of Dimes regarding an insensitive story found on the reverse side of a donation request form we received in the mail. It was the story of a pregnant woman who did everything "right" and nothing "wrong"—her reward was a "perfect baby." We received no reply to our complaint, but were relieved to see them cease using this campaign a short time later.

Newly sensitized, we began to notice other March of Dimes PSA's, like the one with the different sized footprints mentioned in Teresa Wolding's article. On television, we noticed others: The first showed a pregnant woman raising a

continued on page 6

PRODUCT NEWS

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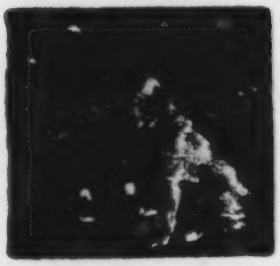

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Circle #31

LETTERS

continued from page 4

glass of beer in a toast while the voice-over said, "If you drink when you're pregnant, here's to birth defects." The second, which aired during Saturday morning cartoons, depicted parents holding healthy, "normal" children and exclaiming over everything they loved about them—their cute little ears, their sparkling eyes, their sweet little noses. Then one individual said something like, "But do you know what I hate?" and then went on to describe the effects of spina bifida.

We asked the March of Dimes how an ad about a child could use the word "hate." They told us they had received the ad from their Texas affiliate, where a certain region of the state had a high incidence of neural tube defects. They said they believed this type of language was needed to reach that population. Outraged, we hung up, resigned to the fact that

continued on page 8

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742, fax. Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication but enables us to contact letter writers directly if necessary.

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***Write to:** Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Suite 303, Brookline, MA 02146, (617) 730-8742 (fax). A sampling of reader responses to this question will appear in a future issue.*

698

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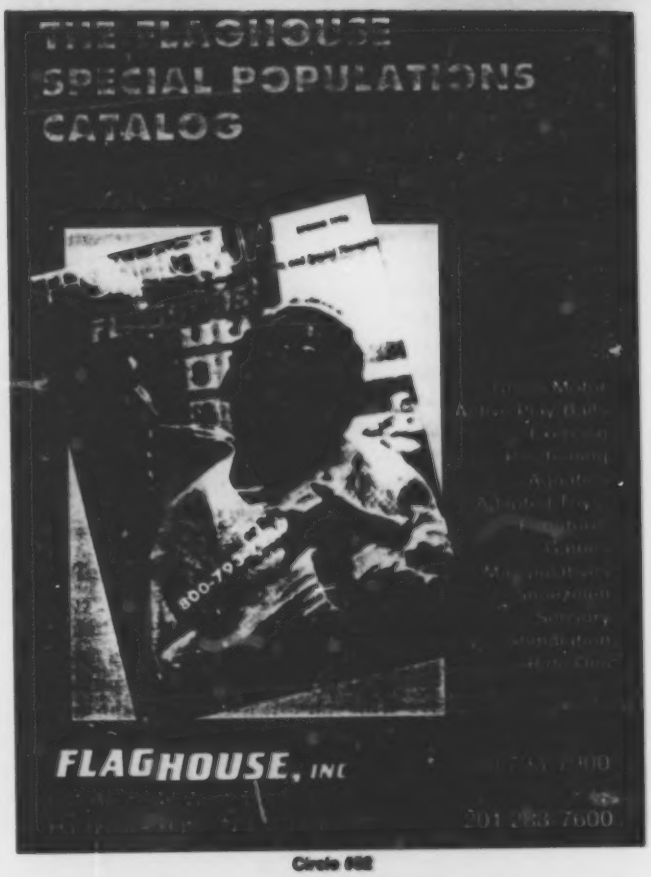

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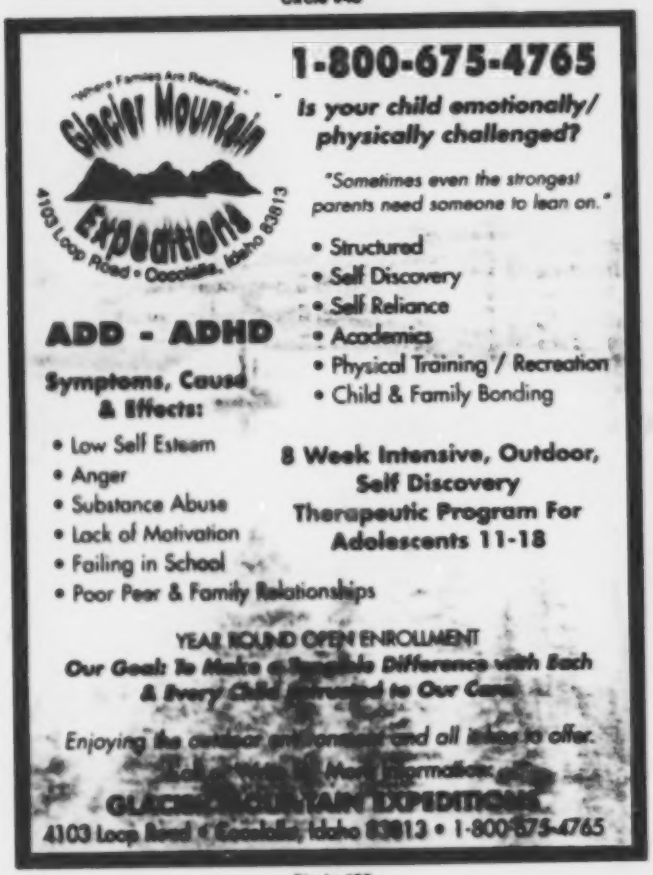

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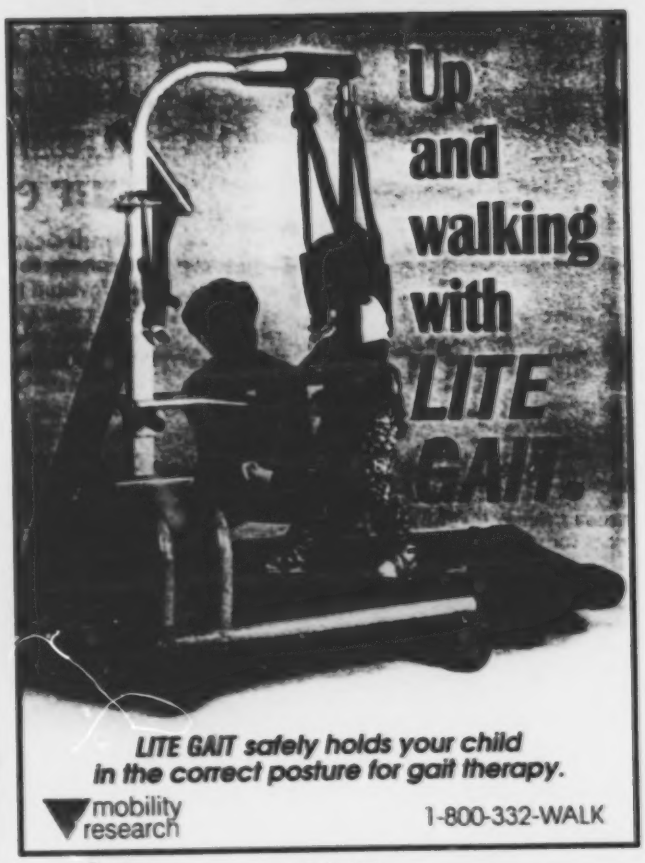

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continued from page 6

these seemingly well-intentioned people simply don't get it!

Well, this mom did everything right, but our son was still born with a birth defect. What happened to him was completely beyond our control. In fact, our son's spina bifida is the result of a genetic condition called Waardenburg syndrome. It's too bad the March of Dimes doesn't have a disclaimer for cases like his.

There are many causes of birth defects, just as there are many causes of premature births. Until we all speak out against these insensitive, shock-value ads, parents of children with disabilities—especially mothers—are going to suffer. We thank God that we can see the beauty in all our children and rejoice in the ways they've touched our lives. We don't love spina bifida; we love our son!

And we feel love for all children with disabilities. Their families face so many obstacles in their everyday lives. Added to these hardships are the public ignorance and prejudice resulting from the slick advertisements of an organization that glibly replies, "We have an obligation to pass this information on to the public and will continue to do so." This is more than we can bear.

The statement from the March of Dimes says they "would be happy to hear from EXCEPTIONAL PARENT readers on this subject."

We say, "Let them have it!"

S.S., New Jersey

■ I share Teresa Wolding's feelings. My two-year-old son was born with myotubular myopathy, a severe skeletal muscle disorder. Because his respiratory muscles are also weak, he is ventilator-dependent. We had no indication of any problem during my pregnancy.

The "campaign of blame" is not limited to premature births. My experiences indicate that the general public and many medical professionals believe that mothers are responsible for *any and all* congenital disabilities. For example, prior to a hospital admission for my son, I received a questionnaire that included the following questions:

- How much alcohol did the mother consume during the pregnancy?
- What drugs did the mother take during the pregnancy?
- How many cigarettes did the mother smoke?

Not "*did* the mother...?" but "how much?" and "how many?" The implication seems clear.

I agree that all pregnant women need to know the effects of alcohol use, drug use and other behaviors on their developing baby, but everyone also needs to understand that maternal behavior causes only a small percentage of birth defects. Professionals caring for pregnant women have an obligation to advise their patients that in spite of medical advances and meticulous prenatal care, many children are born prematurely and/or with disabilities.

No one can ensure a healthy outcome to a pregnancy. There are too many variables, too many unknowns. Of course, it is convenient to blame the mother—much easier than admitting we have no control over a developing baby.

We all feel threatened by what we do not understand and cannot control, but if we are to accept children with disabilities as valuable members of our society, we must accept them as they are. Nobody can ever be fully prepared for the birth of a child with severe difficulties, but much can be done to lessen the shock. Education is the key; blaming is non-productive. At the very least, if the outcome of a pregnancy is "less than perfect," the mother needs to be assured and reassured by doctors, as well as society, that she is not to blame. Only then can she move on to the monumental task of accepting and raising her child.

L.V.M., Wisconsin

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700

B R A U N

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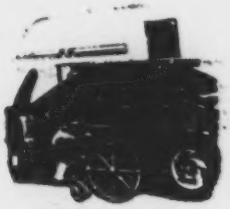

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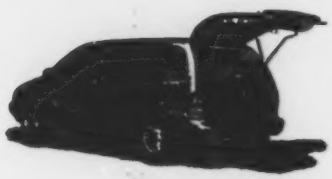

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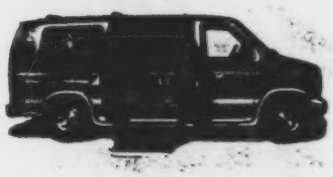
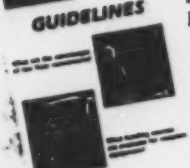


Lift-A-Way® D/C Lift - the latest in Braun's line of personal lifts featuring the ARS (Automatic Roll Stop).



To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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SEARCH

Undiagnosed Neuromuscular Disease

My 18-month-old son has an undiagnosed neuromuscular disease. Cody has an uncontrollable seizure disorder, and has had different types of seizures at different times. Currently, he has tonic-clonic (grand mal) seizures, for which he takes Lamictal and Depakene.

Although many tests, including skin and muscle biopsies, have failed to reveal any diagnosable disorder, we do know that Cody has cerebral atrophy and is missing some white matter of the brain. He has neuromuscular scoliosis (curvature of the spine) and weak, spastic muscle tone. Since Cody's muscle tone makes it difficult for him to manage respiratory secretions, he is susceptible to pneumonia and other illnesses. He also has gastroesophageal reflux.

Cody has severe developmental delays. He does not roll over or sit up, but is beginning to have more head control. He is aware of his environment, especially family and friends. He does not use his hands to grasp toys, but tries to reach for them. Cody enjoys eating. Until last November, he slept through the night. Now he sleeps more during the day.

We have met a few similar boys—none have had a definitive diagnosis. We would love to hear from parents with a similar child.

K.P., New York

Infantile Scoliosis and Horizontal Gaze Palsy

My 26-month-old son, Dylan, has infantile scoliosis (curvature of the spine) and congenital horizontal gaze palsy, meaning he can move his eyes up and down, but must turn his head to follow an object moving horizontally. Researchers believe this condition is caused by a malfunction of the lower brain stem. Only 39 cases of infantile scoliosis with horizontal gaze palsy have ever been reported, and they are all in Europe.

Dylan appeared normal until he was nine months old, when the scoliosis was discovered. At that point, doctors also diagnosed the horizontal gaze palsy; previously, we had not noticed anything abnormal about Dylan's eye movements. He shows no sign of any muscle disease or brain tumors.

Dylan now has a spinal C-curve of 80 degrees. A nighttime brace corrects the curve to 35 degrees, but, as soon as it comes off, it returns to 80 degrees. The scoliosis seems to be progressing by about two degrees a month. Doctors say Dylan will need a spinal fusion soon. We have tried to delay surgery to allow his spine to grow, although it is unlikely we will be able to delay much longer.

I would like to get in touch with anyone who might know of a child with this or a similar condition.

J.B., California

Cerebral Palsy and Toilet Training

Our nine-year-old daughter, Claire, has spastic quadriplegic cerebral palsy. She is a second grader in our neighborhood public school, dividing her time between the regular classroom and the learning disabilities classroom. She is skilled at using her augmentative communication device.

Now we're ready to take on our next challenge—toilet training. She will be able to use an adaptive toileting chair with maximum positioning support. This will work at home and school, but I'm wondering what will happen when she needs to use the bathroom, but does not have the adaptive chair available—when she is out shopping or on a field trip. What solutions have other parents found?

C.M., Mississippi

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EXCEPTIONAL PARENT
The Magazine for Families and Professionals

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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MOST PARENTS OF BED WETTERS THINK THERE IS VERY LITTLE THEY CAN DO TO HELP.

Some 3 million children, 10% of all kids between 5 and 10, wet the bed twice a week or more. If your child is in school, chances are at least two of his classmates are in the same leaky boat. No child should ever feel alone with this problem. But, of course, they do.

The good news: More is known than ever before that can help. Once, the only sure cure was time. 99.9% of our children leave this problem in the dust as they grow. And now there are some ways you can give time a hand.

THE BEST BEGINNING

For starters, pediatricians know a lot more about the causes of "enuresis" (that's the official medical name for it) than they used to.

Doctors today deal with this problem all the time. They have new techniques and sometimes medicines that can help manage bed-wetting, if not eliminate it altogether.

Another advance since *we* were kids: Disposable, absorbent underpants are now made for larger children, 45 to 85+ pounds. By helping our children sleep dry, these pants take a lot of the "mess and stress" out of bed-wetting. Especially for the kids themselves.

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Thousands of families like yours now count on these disposable underpants, created by the makers of Pull-Ups® training pants.

Pull-Ups® GoodNites® absorbent underpants eliminate the rubber sheets and the laundry and much of the stress that make nighttime accidents into a bigger deal than they really are, and make our children feel small. Smaller than they really are.

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If GoodNites underpants are new to you, now is the time to try them. You will rejoice that you did. Thousands more families every month are having success with GoodNites.

GoodNites are not a miracle, but there's nothing else like them. They help families keep bed-wetting in perspective. They help make dry mornings, in crisp clean sheets, routine. And make sleep-overs and other normal, healthy everyday kid things routine, too. The way they should be.

THESE BOOKLETS REALLY HELP

GoodNites underpants were developed with the help of pediatricians and other childhood specialists. You'll find much of their good advice in these little booklets. There's one for parents, and one to help your child be part of the solution, too. For copies, please send $1 for postage and handling to: GoodNites Guides, P.O. Box 1165, Maple Plain, MN 55592.

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Apple

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Oxygen and Bicycles?

My eight-year-old son, Matthew, who needs continuous-feed oxygen, wants desperately to learn to ride a bicycle by himself. I am anxious to help my son become independent in this activity, but first, we must come up with a safe way of carrying a liquid or gas tank on the bicycle.

I have been discussing this issue with our durable medical equipment provider. At this point, we are leaning toward the idea of welding a straight bar over the bike's back tire, angled away from Matthew. The bar would have tank supports large enough to carry a "C" cylinder (a small container holding up to 200 liters of gaseous oxygen). I would like to add a foam-lined carrier over the back tire that would protect the tank and regulator and hold an additional length of tubing that would be available when he falls—if such an item were available.

I'd love to hear others' suggestions or similar experiences. Matthew is also interested in owning in-line skates and a skateboard, but he's agreed to put those wishes on hold—at least until we've come up with a solution for the bicycle project!

M.C.A., Massachusetts

Cri du Chat and Agenesis of the Corpus Callosum

My one-year-old daughter, Heidi, has cri du chat syndrome, a chromosomal disorder characterized by a deletion at the end of the short arm of chromosome 5. Characteristics of this syndrome include a kitten-like cry, an abnormally small head, and mental retardation. Heidi's chromosome-5 deletion (located at 14.1) is larger than typically seen in cri du chat syndrome. This may explain why she also has complete agenesis of the corpus callosum (ACC)—a congenital absence of the band of fibers responsible for communication between the left and right hemispheres of the brain. Heidi has a seizure disorder and severe neurological impairment.

I know of no other children with both cri du chat syndrome and ACC, but I suspect some are out there—possibly children with similar chromosomal deletions. Heidi's doctors have no idea how these two conditions will affect her development.

S.H., Washington

Feeding and Toileting Skills

My four-year-old daughter, Lisa, has autism and severe mental retardation. She is non-verbal. She also has hypertonia (muscle stiffness) and juvenile arthritis, both of which affect her fine and gross motor skills. She can walk, but loses her balance often and tires easily.

We are unable to wean her from her bottle because she won't close her mouth when drinking from a cup. When we work on feeding skills, she throws spoons; her therapist says she is "tactile defensive." Finally, I don't know if she'll ever understand toileting.

I would like to hear how other parents have helped their children acquire feeding and toileting skills. I am also interested in how other parents handle changing diapers on older children, especially out in the "real world."

V.T., Arkansas

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Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, ***EXCEPTIONAL PARENT***, 209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742, fax.

For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812; (800) 999-NORD; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in ***EXCEPTIONAL PARENT's 1996 Resource Guide*** (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8[illegible] (fax).

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Carbohydrate Deficient Glycoprotein Syndrome

I am searching for other parents who have children diagnosed with carbohydrate deficient glycoprotein syndrome (CDGS). My two-year-old daughter, Ashley, was recently diagnosed with CDGS, a genetic disorder for which no prenatal testing is available. Ashley was initially diagnosed with infantile spasms immediately after her second DPT shot at the age of four months. (Infantile spasms is a form of epilepsy identified by a hypsarrythmia brain wave pattern.)

CDGS is a very rare metabolic disorder; many cases go undiagnosed. There are about 150 reported cases in Europe, about 30 known cases in the United States, and individual case reports from many other countries. Manifestations of this disorder may include any number of the following symptoms: failure to thrive, feeding difficulties, developmental delays in the area of voluntary motor skills, hypotonia (low muscle tone), esotropia (a form of strabismus in which one eye turns inward while the other focuses straight ahead), inverted nipples, lipodystrophy (irregular distribution of fat deposits under the skin), cerebellar hypoplasia (underdevelopment of the cerebellum, the part of the brain responsible for maintaining balance and coordinating voluntary movements), coagulation (blood-clotting) defects, severe infections, enlarged kidneys and seizures.

Ashley has hypotonia, developmental delays, several dimples on her thigh and buttock (lipodystrophy) and inverted nipples. She also has complex-partial seizures with apnea that occur every seven to 10 days. Otherwise, she has been a very healthy baby with no feeding problems.

Researchers in Sweden have linked one type of CDGS to a specific area on the short arm of chromosome 16. However, there appear to be other forms of the disorder.

I am hoping to start a support group for this rare syndrome. I would like to hear from anyone who has a child diagnosed with CDGS or who would like more information about the condition.

D.L., Illinois

Puzzling Symptoms

My seven-year-old son has severe developmental delays as a result of a post-immunization encephalopathy (brain disease) that occurred after his four-month DPT vaccination. He functions at a 10- to 12-month-old level in all areas.

Until recently, he didn't have any medical problems other than common childhood illnesses. However, over the past year, he has developed symptoms that have us very concerned. These symptoms—which occur seemingly at random, as often as daily or as infrequently as every few weeks—include fever as high as 102 degrees, high blood pressure, diarrhea, nausea and/or vomiting, major sleep disturbances, itching/tingling especially in the hands and feet, episodes of pain/screaming and periods of bizarre behavior. Although he eats well, he has lost weight and is now very thin. He sometimes stays awake for days on end, then sleeps for nearly as long. Dark hair has grown on the lower part of his left arm and on his back. In the past month, his upper right arm has grown in circumference; it is now visibly larger than the left. He has a hump on the bottom of his right heel that he rubs constantly.

Normally content and happy, he now has periods of aggression, delirium (alternately laughing and crying), incredible activity or listlessness. He can go from one extreme to another in a matter of seconds; one moment, he will be "bouncing off the walls," and the next, he will be asleep. Although these symptoms do not occur together, some type of cyclic pattern does seem to be occurring, with relatively well periods alternating with sick periods.

I can't find a clue as to what is causing all these problems. My son's doctors are also puzzled. I need help in finding a doctor who specializes in difficult-to-diagnose cases. I believe my son needs a very thorough medical evaluation by a team of specialists (not a developmental or rehabilitative evaluation). I am willing to take my son anywhere in the United States. If anyone has a child who has experienced similar symptoms, or can recommend a facility or physician who specializes in challenging cases, I'd like to hear from you.

L.K.G. Louisiana

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Testing is simple and inexpensive. Treatment is available. Delayed diagnosis has been linked to severe developmental disabilities such as mental retardation. Carnitine deficiency caused by metabolic disease can be fatal if untreated.

What is it? Carnitine is a naturally occurring substance that helps turn the food we eat into energy and protects the body from accumulating toxins that interfere with energy production. Babies and young children lack the enzyme to make their own supply of carnitine, but in most cases obtain the necessary supply from dairy products, breast milk, infant formula and red meats in their diet. Infants and children may be carnitine deficient due to a failure to transport carnitine into the cells. This is called primary carnitine deficiency. A deficiency resulting from poor dietary intake or a metabolic disease which depletes the body's stores of carnitine is called secondary carnitine deficiency.

What are the symptoms? Very poor muscle tone and coordination, chronic vomiting and fever, severe feeding problems, failure to thrive, little weight gain and/or weight loss, lethargy and unusual weakness, recurrent infections, flu-like symptoms, seizures or loss of seizure control, liver dysfunction and poor cardiac function.

What can you do? Consider the possibility that your child has a metabolic disorder if traditional treatments for a health problem don't seem to be working. Ask your pediatrician to check your child's carnitine plasma level. Be aware that carnitine deficiency is a symptom of metabolic disorders and further examination by a metabolic disease specialist is needed. Treatment for carnitine deficiency is simple and fast acting in acute cases. Contact Assistance for Babies and Children with Carnitine Deficiency for more information and support.

A parent-founded organization which serves as a source of support and guidance for the families of carnitine deficient children.

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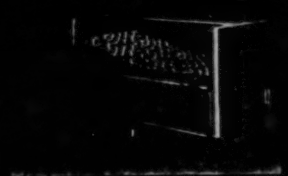

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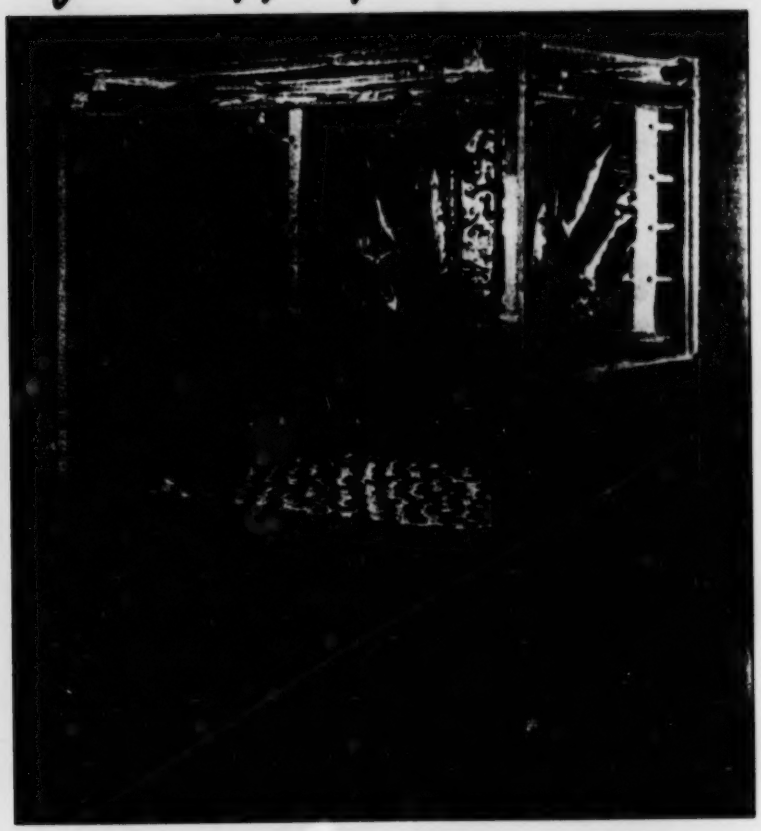

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RESPOND

Loss of Skills

C.E. (March 1996) has a four-year-old son with cerebral palsy, who has lost many previously attained skills. In the last six months, he has gone from being able to repeat phrases and name objects, letters and numbers to saying just one or two words a day. He lost his ability to stand, became uninterested in books and developed irregular sleeping patterns, sometimes staying awake and laughing all night. Neither an MRI nor an EEG have provided any clues. C.E. was searching for information and advice.

I was struck by the similarity in our children's histories. Our daughter's experience parallels your son's in a number of ways. Emalyn's deterioration also occurred over a six-month period—between the ages of two and a half to three. During that time, Emalyn lost most of her expressive language, retaining only some largely unintelligible jargon. Her receptive language sometimes seemed impaired, too, leading us to suspect deafness. She no longer pointed, named pictures in books, told us her needs, used communicative gestures or played appropriately with toys; but sometimes, out of the blue, she would spontaneously recite rhymes or sing songs. Emalyn became withdrawn and spent long periods occupied in solitary, repetitive activities. She resisted our attempts to engage her with activities she formerly enjoyed. She also laughed and cried for no apparent reason. Her activity level increased and disrupted her sleep, leaving her tired and irritable. She also developed an odd gait and seemed to be experiencing muscle weakness.

At four and a half, after seeing several specialists and having an MRI and EEG (neither showed signs of brain damage), she was diagnosed with pervasive developmental disorder (PDD)/autism. Over the next four years, she received intensive therapies and interventions designed to address this condition. Although she has made some progress, she continues to experience regressions from time to time.

Recently, doctors have suggested that Emalyn may be experiencing some underlying, undiagnosed seizure disorder that disrupts the language, emotional, behavioral and motor areas of her brain. Routine daytime EEGs often do not reveal this type of seizure activity, which may occur only for a brief period during the evening or during deep sleep. Sleep disturbances may be initial symptoms. Seizure activity may increase when the child is overtired, stressed or anxious. The seizures can occur every one to four seconds, lasting less than a second each time, but are not visibly detectable, even by a trained neurologist. They can only be detected by an EEG that is done without sedatives after the child has been sleep-deprived for an extended period—24 hours or more is best. These seizures can also be detected through either PET (positron emission tomography) scans or SPECT (single photon emission controlled tomography) scans.

L.H. & L.H., New Jersey

Nemaline Myopathy

D.H. (April 1996) is the primary caregiver to her 10-month-old grandson, who has nemaline myopathy (also known as congenital rod disease or rod myopathy), a congenital disease of the skeletal muscles. He has a gastrostomy tube and a tracheostomy, and is on a bi-pap machine to aid his breathing. D.H. was looking for more information about how to help her grandson and what to expect in the future.

Nemaline myopathy is one of 40 neuromuscular disorders falling under the umbrella of the Muscular Dystrophy Association (MDA, 3300 E. Sunrise Dr., Tucson, AZ 85718-3208; 800/572-1717). MDA's national office can direct D.H. to the nearest MDA office or clinic, where she and her

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FUNNY AS A CRUTCH by Frank Bernard, Jr.

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grandson can receive a variety of services. The local MDA affiliate can also put D.H. in touch with other families like her own and with support groups.

MDA serves individuals with various myopathies, all forms of muscular dystrophy, metabolic diseases affecting the muscles, diseases of the peripheral nerves and other neuromuscular diseases. Any family with a child affected by one of these disorders is eligible for MDA services.

Robert Ross
Senior Vice President &
Executive Director
Muscular Dystrophy Association
Tucson, Arizona

■ It is hard to make direct comparisons between children with nemaline myopathy because the extent of muscle weakness tends to vary from child to child. But my daughter, Miriam, also has nemaline myopathy, diagnosed at 14 months, and perhaps our experience will be helpful to you.

Soon after birth, Miriam was sent to the NICU due to extreme weakness and an inability to feed. We brought her home after learning how to bottle feed her—a slow and tedious process. When she was a year old, the doctors finally made the decision to insert a gastrostomy tube (g-tube), and then a g-button. Miriam immediately began to thrive and, now, at three and a half, has caught up to her peers in height and weight. She has been sick a few times a year, but has not had pneumonia or respiratory distress.

We began aggressive physical and occupational therapy when Miriam was three months old. The process is tedious, painful and slow, but progress has been steady. Though Miriam can barely crawl and cannot get up from the floor, she began walking independently at the age of two and a half. She loves to walk, although she must ask us to put her in standing position before she can go. From seeing similar children, we expect that she will be able to get up to a standing position independently within the next year.

Like your child, Miriam has always been very alert. She is a sweet child—although she is developing an independent streak of late! She learns easily and has a sense of humor. She attends a special class for preschoolers with physical disabilities and loves it. Because she can lose her balance easily, she wears a custom-made soft helmet while in school.

Despite all of the research we have done, we still do not know the prognosis for children with this condition. My wife and I are always eager to compare notes with other parents. We all have our frustrations, but the high points are amazing.

G.S., California

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continued from page 20

Dystonia

D.M. (May 1996) has a two-year-old daughter whose original diagnosis of spastic quadriplegic cerebral palsy was recently revised to non-progressive dystonia, a rare muscle-tone disorder. She has been placed on a medication called Sinemet. D.M. wanted to hear from other parents who have had experience with this diagnosis.

My 28-month-old daughter, Hannah, has dopamine-responsive dystonia, a condition affecting her overall muscle tone, but most critically, the muscles involving swallowing. At birth, she had no natural suck or swallow reflexes. Numerous tests, including two MRI scans, showed no sign of brain damage. She then had two spinal taps, several months apart, both of which showed that her level of dopamine, a chemical messenger in the brain, was 50 percent lower than normal. It also showed low levels of the enzyme that facilitates the dopamine production.

Those findings led Hannah's neurologist to send us to the National Institutes of Health (NIH), where we became involved in a study of 10 families that include members with a wide range of muscle-tone disorders. Our link to this study was the fact that my father was diagnosed with Parkinson disease at the relatively young age of 55. Since the time of his diagnosis, he has taken Sinemet (carbidopa-levodopa, the synthetic form of dopamine). Because he has responded so well to this treatment, doctors now believe he doesn't really have Parkinson disease, but has the same condition as Hannah, only with a later age of onset. My dopamine levels are also low as it turns out, but not as low as my father's or Hannah's.

In addition to muscle-tone disorders, some members of the 10 families involved in the NIH study have been diagnosed with manic-depression and obsessive-compulsive disorder, both of which have also been associated with abnormal levels of dopamine.

Hannah has been taking Sinemet for the last 18 months, and we have seen positive results. She can crawl now and is beginning to pull herself up to a stand, but has not started taking steps. I attribute a lot of her progress to the continuous physical and occupational therapy she receives. Hannah's speech is delayed—she has just started making sounds and trying to form words. Because of her weak swallow, she cannot eat orally, but has a gastrostomy button; we have to frequently suction her secretions.

T.K., Texas

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Telling David's Story

One father's fight to increase the safety of childhood vaccinations

by John Salamone

Today my six-year-old son, David, started karate. To most parents, such an occasion would be one of many proud events in the growth of their child; however, for my wife, Kathy, and me it was much more. Only five years ago, David contracted polio and we thought he might never walk.

It was in the fall of 1990 when we, like millions of other parents, brought our seemingly healthy baby to the pediatrician for his routine vaccinations. David cried as the doctor and nurses administered his shots and oral vaccination. The memory of that cry still haunts me, as I now realize what we brought upon David that day.

Within 48 hours David had a high fever and rash, and, within weeks, our active baby boy could no longer use his legs to crawl. Our son had contracted polio from the vaccine that was supposed to protect him. (We later learned that David was born with a genetic disorder known as Brutons agammaglobulinemia, which left him with only a limited immune system and made him vulnerable to the polio vaccine he had been given.)

Disbelief turns to anger

Kathy and I felt a myriad of emotions when we learned David had contracted this dreaded disease, which only 40 years ago had afflicted millions. Our disbelief quickly turned to fear as we looked ahead to an uncertain future for our only son. We also felt guilty, since by providing for David's vaccinations we had unwittingly participated in making him a victim of polio. But we were also angry, and the more we learned, the angrier we became. Why didn't our doctors tell us about potential risks and options? We finally decided to channel our anger into a crusade to ensure that other children would not suffer the same fate.

I began to research the U.S. polio immunization program. I was especially interested in comparing the original Salk vaccine to the Sabin vaccine developed several years later. Both vaccines share the credit for the virtual eradication of polio in the United States. However, the Sabin vaccine became the vaccine of choice for several reasons: 1) it was orally administered (the Salk vaccine needed to be injected); 2) it was believed that this "live" vaccine would be more effective than Salk's "killed" vaccine; and 3) the Sabin vaccine was less expensive to produce. For the sake of an easy-to-administer and cost-effective universal vaccination program, the government decided to promote the oral Sabin vaccine, even though it was known that a small number of children each year would actually contract polio from it.

Telling our story

I began a letter-writing campaign in earnest. I wrote letters to the Centers for Disease Control and Prevention (CDC), to individual members of a working group that had been established to explore possible changes in our national vaccine program, to members of Congress and even to President Clinton. I talked to the National Vaccine Information Center (NVIC) to share our experience and ask for any information or help they could provide. Finally, thinking I could take my case directly to the people, I also sent dozens of letters to medical reporters across the country. My message was simple: Since wild polio has not existed in the United States for nearly 20 years, isn't it time that the government began to encourage the use of the effective and safe killed polio vaccine to prevent more victims like David?

For several years, it seemed no one was interested in our story. Finally, in

continued on page 24

Dad's backseat driving doesn't seem to bother four-year-old David. David won this sporty convertible in a raffle at the annual picnic of the California State Society, an organization for California natives who, like David's mother, Kathy, now reside in the Washington, D.C. area.

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Before You Vaccinate Your Child

The National Vaccine Information Center (NVIC) recommends asking seven questions before you vaccinate your child:

1. Is my child sick right now?
2. Has my child had a bad reaction to a vaccination before?
3. Does my child have a personal or family history of vaccine reactions, convulsions or neurological disease, severe allergies, or immune system disorders?
4. Do I know if my child is at high risk of reacting to a vaccine?
5. Do I have full information on the vaccine's potential side effects?
6. Do I know how to report a vaccine reaction?
7. Do I know the vaccine's lot number and the name of its manufacturer?

Each vaccine—whether live-viral or inactivated-bacterial—is associated with specific potential side effects and contraindications (conditions that should preclude vaccination), so it is important that parents are fully informed. The product manufacturer's package insert that, by law, accompanies vials of vaccine is a good source of information. The American Academy of Pediatrics has also developed vaccination guidelines (see sidebar on page 25). Parents have many factors to consider when making a vaccination decision, and becoming better educated about childhood diseases and vaccines can help you make the best choices for your child.

—Barbara Loe Fisher
National Vaccine Information Center

The NVIC is a non-profit organization dedicated to preventing vaccine-associated injuries and deaths through public education. The NVIC was instrumental in the creation of the National Childhood Vaccine Injury Act of 1986. Today, the NVIC monitors vaccine research and development, policymaking and legislation. The organization offers many sources of information, including a national bimonthly newsletter. For more information, contact NVIC, 512 W. Maple Ave., #206, Vienna, VA 22180; (800) 909-7468; (703) 938-3783; (703) 938-5768 (fax); kwnvic@aol.com (e-mail).

continued from page 23

June 1995, the NVIC asked me to appear before a CDC committee at a conference in Washington, where I and other parents would testify about our experiences with vaccinations that had caused disabilities. After four years, I finally had the chance to tell the stories of David and the more than 100 other children who had contracted polio from a live vaccine over the past 10 years.

I knew that this was my one chance to be heard and that I had to present the most persuasive case possible for changing the polio vaccine program. As vividly as possible, I described David's daily struggles and physical therapy. I told of our sadness as we watched him try to keep up with other children at the playground, and I explained how other industrialized countries had already changed to a killed vaccine program, with no cases of vaccine-related polio in decades.

A few reporters attended the meeting, and within days there was a newfound interest in David's story. The *Washington Post* wrote an article about my testimony, followed by a six-page cover story in their Health section. The Associated Press ran a wire story and photograph of David. *USA Today* decided to do a feature on David, and the television program *Inside Edition* devoted an entire segment to his story. One day, my wife called me at work because a CNN film crew had just appeared at our door. The NVIC received more than 20,000 telephone calls as a result of this coverage.

One voice can make a difference

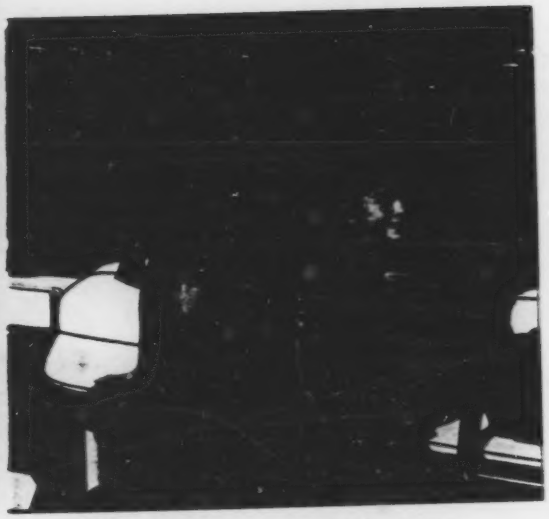
In October 1995, the CDC proposed the first changes in the polio vaccine program guidelines in more than 30 years. They could no longer justify that the only cases of polio in the United States each year were those contracted as a direct result of the oral polio vaccine. The proposed guidelines provide that the first two childhood polio immunizations use the killed vaccine delivered by injection and seem to imply that the ultimate goal would be the eventual elimination of the live oral polio vaccine.

One month after this decision, the Secretary of Health and Human Services asked me to serve on the Advisory Commission for Childhood Vaccines. I accepted with the hope that one voice can still make a difference. I will need that voice, since the manufacturers of the oral polio vaccine are taking legal action against the newly proposed CDC guidelines, which are scheduled to go into effect later this year.

A story of hope

David is now in first grade. It sometimes seems that he spends more time with doctors than with other children. With the help of a leg brace he can walk, but he tires easily. He calls his

David, an enthusiastic karate student, fools around with sister Liz, 12, outside their Oakton, Virginia home. Liz has also become an advocate for David's cause; she has written several school papers arguing the case for a return to the Salk vaccine.



While his sister, Liz, appears to have some reservations, David, 5, looks eager to try parasailing—soaring in the air on a parachute-like device while tethered to a fast-moving boat.

Despite these challenges, David's story is a story of hope, not despair. Nothing keeps him from doing the things other kids do. Last year, we took him skiing and he couldn't wait to hit the slopes. During the Blizzard of '96, David rallied our neighborhood kids for sledding and building snow forts. He recently told my wife, Kathy, that he wants to take gymnastics like his sister Liz. Why not?

I am not sure David will ever become a black belt in karate, but I do know he will try. As he gets older, I hope he will realize that he has achieved much more—he helped to ensure that hundreds of children from his generation will not be crippled by polio. **EP**

John Salamone lives in Oakton, Virginia, with his wife, Kathy, and children, Liz, 12, and David, 6. John is Special Projects Director of the National Italian-American Foundation in Washington, D.C. Kathy was a guidance counselor at J.E.B. Stuart High School in Falls Church, Virginia, for 20 years. Liz is a seventh-grader at Frost Intermediate School in Fairfax, Virginia, and David attends first grade at Oakton Elementary School.

physical therapist the "toy doctor" because of the playthings used in his therapy sessions. He has no special names for the other doctors—neurologists, physiatrists, rheumatologists and orthopedists—who have become a regular part of his life. He will live with infusions of gammaglobulin every four weeks and daily doses of antibiotics for the rest of his life. He has also been left with arthritis and pulmonary deficiency.

What Parents Should Know About Vaccination

Why should I get my child vaccinated?

Your child needs vaccinations (shots) to protect against many serious contagious childhood diseases. Today, many children are needlessly catching dangerous diseases like measles, whooping cough, hepatitis and meningitis. Without vaccinations at the right times, your child could get one of these very serious or even fatal illnesses.

What can happen if I don't get my child vaccinated?

Without vaccinations, your child can catch diseases that can cause high fever, coughing, choking, breathing problems and brain damage. These diseases may leave your child deaf or blind or cause paralysis.

Are vaccinations safe?

Reactions to vaccines may occur, but they are usually mild. Serious reactions are rare but may occur. Remember, the risks should your child get one of these dangerous childhood diseases are far greater than the risk of a serious reaction from a vaccination.

The above is an excerpt from WHAT PARENTS NEED TO KNOW ABOUT VACCINATION AND CHILDHOOD DISEASE. *For a free copy of the booklet, send a self-addressed, stamped envelope to the Academy of American Pediatrics, Dept. C, Immunizations, P.O. Box 927, Elk Grove Village, Illinois 60009-0927.*

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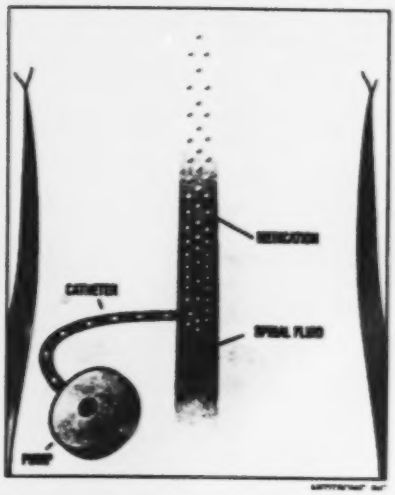
Health

New Treatment for Cerebral Palsy

An innovative new therapy is now available for children and adults with the chronic muscle stiffness, or spasticity, that is often associated with cerebral palsy and brain injuries. When muscles are spastic, individuals often cannot move well enough to do things like feeding or dressing themselves, writing or walking. The new therapy allows muscles to relax, thus helping people to move and maintain posture and balance more easily. This new treatment option, specifically for individuals with spasticity, involves a combination of pharmaceutical and implantable device technologies.

The new treatment is called Intrathecal Baclofen (ITB) Therapy because a catheter extending under the skin from the implanted Medtronic SynchroMed Infusion System delivers a concentrated formulation of the drug baclofen directly to the fluid surrounding the spinal cord. This direct delivery makes the difference in achieving significant decreases in spasticity with minute doses of the drug. Baclofen taken by mouth is ineffective and not indicated for this use.

Marketing approval by the U.S. Food and Drug Administration (FDA) was announced on June 19, 1996. The FDA previously cleared the pump-baclofen therapy for treatment of spasticity of spinal-cord origin in individuals with spinal cord injuries or multiple sclerosis. The new therapy was studied for more than eight years at the Children's Hospital in Pittsburgh (as well as at other centers) under the direction of A. Leland Albright, M.D., chief of the Department of Neurosurgery.



Once implanted and programmed, the SynchroMed pump delivers the correct dosage of baclofen through a small-diameter catheter that is inserted into the spinal fluid surrounding the spinal chord.

For many individuals, this treatment can lead to improvements in spasticity that mean dramatic differences in self-care and movement. In clinical studies, the new therapy maintained long-term reductions in muscle spasticity in both children and adults. Some individuals experienced improved speech, swallowing and alertness.

Possible side effects include dose-related sleepiness, nausea, headache, muscle weakness and light-headedness. Most of these symptoms are temporary or can be alleviated through a change in the dose of the medication. Although this new treatment option significantly improves function, it is not a cure for cerebral palsy. **EP**

The September issue will include a more detailed report of this exciting news.

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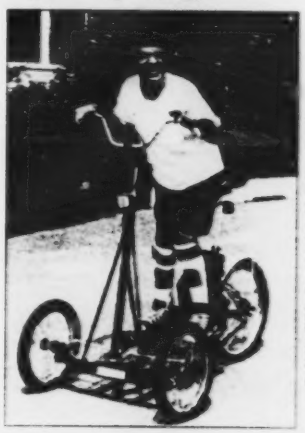

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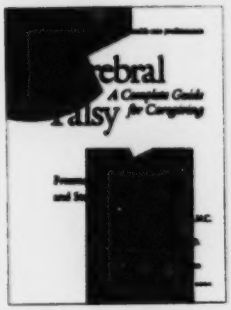
MEDIA

Written by a team of experts associated with the Cerebral Palsy Program at the Alfred I. duPont Institute in Wilmington, Delaware, CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING addresses the many complexities and uncertainties related to this diagnosis. At the same time, it provides the information parents, grandparents, caregivers and health professionals need—everything from medical, educational and psychosocial implications to wheelchair maintenance and dental care. The book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt.



Incontinence

(URINARY INCONTINENCE, BOWEL INCONTINENCE)

Incontinence is defined as the inability to prevent the accidental loss of urine or feces. Incontinence is normal for the newborn baby, but most children are toilet trained by age 3. However, urinary incontinence (enuresis), especially at night while sleeping (nocturnal enuresis), is a common condition and usually does not need a medical evaluation until the child is close to age 6.

Generally, achieving normal bladder control requires the following steps: (1) an awareness of the bladder as it contracts; (2) the ability to realize the state of a full bladder and to plan ahead to go to the bathroom; (3) the ability to inhibit early contractions and postpone urination, and to facilitate the emptying reflex when circumstances are right; (4) an awareness that the bladder has emptied completely; (5) the ability to hold urine when the bladder is overfilled or during momentary stress by voluntarily contracting the muscles of the pelvic floor; and (6) the ability to inhibit emptying during sleep. Thus, a child needs to be developmentally ready before he can be toilet trained, and the child with mental retardation or a developmental delay may be toilet trained at a later age than other children.

Incontinence may also be caused by physical problems, including a urinary tract infection or an abnormality of the urinary system. In the child with cerebral palsy, the nerves going to the bladder may not be functioning normally, and may cause either involuntary emptying of the bladder or abnormal retention of urine to the point that the bladder "overflows" and urine dribbles out. These two conditions aren't common, but may occur in the child with cerebral palsy, although they occur far more frequently in children with other neurological disorders such as spina bifida.

Indications

A child who is incontinent beyond the expected age of 3 or 4, and who otherwise is developmentally normal, should have a good physical examination, a urinalysis, and a urine culture. With the child with cerebral palsy with normal cognitive function, the problem may lie in his physical ability to get to the toilet or his inability to sit up on the toilet. This latter problem is not just physical but also psychological: the toilet seat may evoke fear in the child who feels as if he is going to fall, and thus he may not be able to relax enough to cooperate in toilet training. There is equipment available to help support a child sitting on a toilet.

If tests show that the bladder and kidneys are normal, then behavior modification techniques may be used to teach the child bladder control. These should include a conditioning technique such as a reward system or an alarm system, or alternatively using medication such as imipramine or DDAVP. In the child over age 6 who is still incontinent, x-rays of the kidneys may be done.

Incontinence of stool is not an uncommon problem. Constipation is very often the cause with a child who has previously been toilet trained and then begins to have fecal soiling. What happens is that the child builds up a large mass of dry stool which is difficult to pass, and then liquid feces flow around this mass past the sphincters. Fecal incontinence caused by such an impaction is often mistaken for diarrhea, because the stool that is escaping is liquid.

Fecal incontinence may also occur when the toddler-aged child is stressed, such as during the birth of a sibling or a death in the family. If soiling begins at the time of toilet training, it is best to back off and stop the training for awhile, as this is a sign that the child simply is not emotionally prepared to be trained. Incontinence of stool is commonly seen if the child is mentally retarded or has severe constipation. Cerebral palsy by itself is almost never the cause of failure to become continent. If the child is developmentally age appropriate but is still soiling, an evaluation is in order, looking for constipation or neurological problems as the cause.

Excerpted from CEREBRAL PALSY: A COMPLETE GUIDE FOR CAREGIVING by Freeman Miller, M.D. and Steven J. Bachrach, M.D. (with Marilyn L. Boos, R.N.; Linda Duffy, P.A.-C.; Douglas T. Pearson, Ph.D.; Rhonda S. Walter, M.D. and Joan Lenett Whinston). Published by The Johns Hopkins University Press, 1995.

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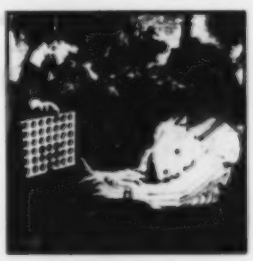

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Familiar Faces

Leah Hadick, 14, and her four-year-old brother, **Timothy,** visit with "Miko" of *Pocahontas* fame on a recent trip to the mall. In fact, Leah can often be found at the mall where, according to her father, Clay, she loves to "shop 'til she drops." Leah lives in Ijamsville, Maryland, with her parents, Clay and Dianna, her grandmother, Marilyn, and her brother, Timothy. Leah, who has spastic quadriplegic cerebral palsy, is an enthusiastic participant in her school's Mobility Opportunities Via Education (MOVE) program.

Outdoor lover **Nicki Cramer** of Dayton, Minnesota, helps her dad, **Doug,** build sand castles on a recent camping trip. Nicki, 7, enjoys yearly family road trips to Walt Disney World, swimming, swinging and playing in the sand. She's also an avid camper. Her parents, Doug and Rose, describe their very busy daughter as the "light of their lives." Nicki has amniotic banding syndrome, a result of fetal constraint due to a deficiency of amniotic fluid in an irregularly shaped uterus. In Nicki's case, the condition led to a below-knee amputation and severe developmental delays.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT? *Send it to: Readers' Photos,* EXCEPTIONAL PARENT, *209 Harvard Street, Suite 303, Brookline, MA 02146. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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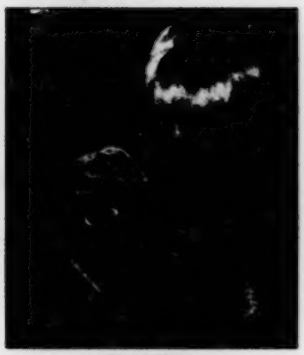
Three-year-old **Jacob Gareth Walker** adores his younger sister, **Taylor,** 18 months. Together they enjoy reading books, watching television, riding bikes and visiting their grandparents' house. Jacob, who has monosomy 15 and Prader-Willi syndrome, lives in Chichester, New Hampshire, with Taylor and his parents, Evan and Tracy.



Sesame Street fan **Cormac Hope Currin,** 16 months, displays what his mother refers to as "his infamous monster face." Cormac, who has Down syndrome, lives with his parents, Christopher Currin and Holly Hope, in Dallas, Texas. He loves books, cats and—most of all—fuzzy, blue monsters.

Despite a busy, full-time preschool schedule, **Travis Allen Bishop,** 3, can always find time for his favorite pastime—playing cowboy! He also loves watching rodeos on television. Travis, who was born prematurely and has cerebral palsy, lives with his parents and three siblings, Heather, 11, Brian, 6, and Kimberly, 5, in St. Augustine, Florida.

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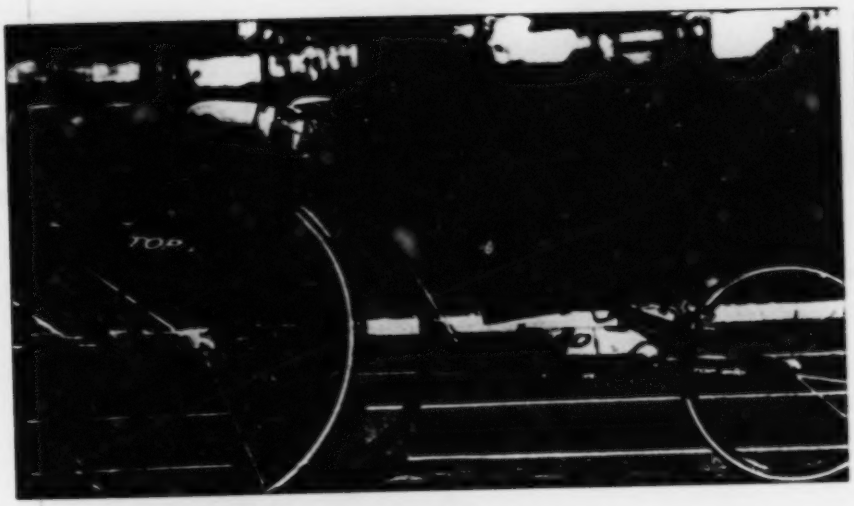

Linda Mastandrea is already looking to the Sydney Games in 2000. "By then I'll be 36," she says, "which in the non-disabled world is really old to be a competitor, but in wheelchair sports, it seems people stay in it longer and are still competitive." Photo: Mary Carol Peterson; courtesy of Top End by Action.

Linda Mastandrea

Going the distance

Linda Mastandrea, 32, a member of the U.S. Paralympic team, will compete in this year's games in Atlanta, in the 100 and 200 meter races for athletes with cerebral palsy and in the 500 meter race for wheelchair athletes.

Mastandrea, who has cerebral palsy, was born in Chicago, Illinois, and grew up in suburban Chicago. She graduated from the University of Illinois in 1986 with a degree in Speech Communication, and received her law degree from Chicago-Kent College of Law in 1994. Her law practice focuses on the Americans with Disabilities Act and other disability laws. Mastandrea also works at the Wirtz Sports Program at the Rehabilitation Institute of Chicago and is a frequent public speaker.

Mastandrea is an athlete representative on the Atlanta Paralympics Organizing Committee, vice president of the United States Cerebral Palsy Athletic Association and a board member of Wheelchair Athletics of the USA. The following was adapted from an interview between Mastandrea and EXCEPTIONAL PARENT *intern Susanne Schmermbeck-Carter.*

My twin sister, Laura, and I were born one month prematurely. My mother hemorrhaged just before we were born and almost died. The doctors later said I probably didn't get any oxygen because she lost so much blood. But I seemed fine when I was born—just small.

Mentally I developed the same or even better than my sister. But when Laura started walking, and I didn't, my parents took me to a neurologist. I was diagnosed with cerebral palsy when I was three years old. I have an older brother and sister, Bobby and Donna, who are also twins. They were 15 when we were born. My other brother, Tony, is one year younger than them.

A "normal" life

My cerebral palsy only affected my legs. I had a lot of physical therapy, but the doctors decided against making me use braces or other mobility aids because they thought these devices would slow me down. They wanted me to lead as "normal" a life as possible. As a child, I didn't use a wheelchair. I tried to do everything my siblings did. If I was walking and got tired, they'd piggyback me. So I got used to being carried around.

I was teased occasionally, especially in elementary school. I especially remember one incident when a kid called me "creepy crawler." The teacher made him apologize in front of the class, which was even worse. It was awful and embarrassing. I was brought up to not think of myself as different.

My teachers had high expectations for me. I think they realized I was really smart. I advanced from first to second grade in half a year. They were going to let me skip a grade, but we moved.

The transition into the new school was difficult at first. But it was easier with Laura there. Also, I was a very social kid. I remember even in first grade just going up to people and saying, "Hi, I'm Linda. What's your name?" I don't think that my disability made me shy. I was always very outgoing.

The dating game

I had a lot of friends, but I didn't date anybody from school. A couple guys asked me out, but I wasn't interested. My first boyfriend was five years older than me. I was 15, and he was in college. In high school, people were very appearance-oriented. I was good enough to be somebody's friend, but not really good enough to be their date. Older guys were past that sort of thinking.

"Come and play with us"

Laura and I decided to go to the University of Illinois, where I first became aware of sports for people with disabilities. I still wasn't using a chair.

continued on page 46

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Circle #22

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but the campus was so big that I sprained my ankle from all the walking.

At the rehab center where I was getting physical therapy for that injury, the school's wheelchair basketball coach, Brad Hadrick, came up to me in his wheelchair and introduced himself. He asked, "Have you heard of wheelchair basketball? The University of Illinois has the best women's team. We would love for you to come out and play." I had never sat in a chair nor been an athlete before. So I just said, "Yeah, whatever."

But Brad and the players on his team kept calling me for about a year, saying, "Come see a practice; come see a game." Finally, I went to a practice. I was really slow because I had never played. I couldn't shoot and I wasn't very coordinated. But they all kept saying, "It's so great that you are here. We really want you to play."

Christmas 1986: (from left) Bobby with Linda, mom Dorothy with Laura, Donna, Tony and Moose the dog. Says Linda, "The older kids really liked taking care of Laura and me, which was kind of unusual because not many teenagers like taking care of little sisters."

Suddenly, I wanted to try this, because they thought I could do it. It was an amazing thought. I played for the next three years. I never got great, but a whole new world opened up for me.

At that point, I was only using my wheelchair for sports; afterwards, I would get up and walk. I remember on team road trips, everybody would be zooming along in their chair, and I'd be walking. When I started to get stress fractures in my feet, and had to get casts and crutches, I said, "This is stupid. I have casts on and I'm still trying to walk."

A dream come true

I got interested in track in 1988, while watching the Seoul Olympics on television. Two of my friends were competing in a wheelchair exhibition race. I remember watching and being in awe. These were people I knew! I thought, I really want to do this.

In 1990, I started racing competitively through the Chicago Wirtz Sports Program, housed in the Rehab Institute of Chicago. The program originally just had wheelchair basketball teams. By 1990, they also had a track team. In 1991, I qualified for the Barcelona Paralympic team for athletes with cerebral palsy. My dream was coming true.

I made the trip, but as it turned out, I didn't have any events to compete in.

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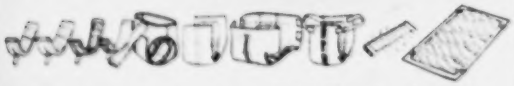

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Linda's father, Bob, congratulates her with a hug after her University of Illinois wheelchair basketball team won the Nationals in March 1986.

The rules were that there had to be six competitors from at least four countries to run an official medal event. There were only five of us, so we ran in a demonstration race. It was just like competing in an official race—and I won—but we didn't get medals.

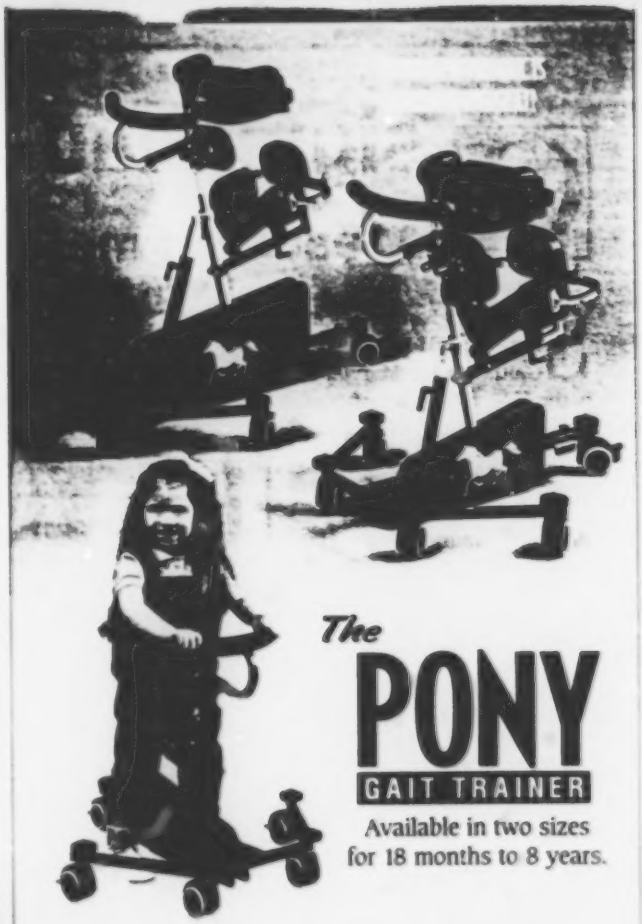
After Barcelona, I had a choice: I could hang it up or keep training to make myself as good and as fast as I could be. In the 400 meters in Barcelona, I had been 15 hundredths of a second off the world record—one push too slow. That became my focus—I wanted to break those records and do it in front of many people. I wanted what I had missed out on. At the 1994 World Championships in Berlin, I had real people to race against, real official events in the program, and I broke the world records in the 200 and 400 meters. Now I'm looking forward to Atlanta.

Sports can give so many things

Parents of children with disabilities seem to be afraid that their children will get hurt or fail. Some parents are afraid to encourage children with disabilities to get involved in sports. But between the friendships, socialization, competition and fitness, sports provides so many benefits. My involvement has given me a whole new focus and direction, and a whole new set of abilities. I learned to be part of a team and to set goals. Sports teaches so many things. Not every kid is going to be a Paralympic athlete, but not everyone wants to be.

Linda celebrates her 1994 graduation from law school with family, friends and a "singing telegram." About her law practice, Linda says, "Sometimes I'm very fired up about it and I think I can change things, but on other days I think no matter what I do there will be ignorant people. One time we went in for a settlement conference and the judge assumed that I was the plaintiff. She didn't even consider that I could be counsel."

To parents of children with disabilities, I would say: Don't lower your expectations. Just because a kid has a disability doesn't mean you should expect less of them than of their able-bodied siblings. Certainly, the demands you place on the child depend on his or her abilities, but every kid wants to be included at some level. There's a fine balance between acknowledging children's differences and not treating them special because of those differences. Let kids know that their disabilities can give them the opportunity to do some things other folks can't do. If I didn't have cerebral palsy, I wouldn't be doing the stuff I'm doing today. **EP**



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Sigma-Tau's main research facilities are located south of Rome, in Pomezia, Italy. Recent expansions have created new laboratories for chemical research, industrial pharmacology, and an Institute for Research on Aging. A cardiovascular pharmacology research center is located in Milan. Sigma-Tau subsidiary offices are maintained in the United States, Germany, France, England, Spain, Switzerland, the Netherlands and the Sudan. Sigma-Tau employs over 2,000 people.

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"The Challenge of Treating Children With Chronic Illness"

Monday June 24, 1996

Children's National Medical Center
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Illustration by Shawna White, Age 6, Huntington, Maryland

Advocacy groups and community involvement

Sigma-Tau has provided financial support for various patient advocacy groups, including the Alzheimer's Association, Alzheimer's Disease International, Assistance for Babies and Children with Carnitine Deficiency, the Fatty Acid Oxidation Disorder Network, the French Foundation for Alzheimer's Disease, the Mitochondrial Disorders Foundation of America, the National Organization for Rare Disorders (NORD), Neurofibromatosis, Inc., and the Organic Acidemia Association.

In addition, Sigma-Tau is active in local community organizations such as The Arc of Montgomery County and HEROES (Honor Every Responsible Officer's Eternal Sacrifice). Sigma-Tau recently created the Claudio Cavazza Science Awards, a summer program that enables Montgomery County public school students to participate in internships at the Food and Drug Administration.

Other contributions include providing for three Young Investigator Awards through the Child Neurology Society, the American Academy of Pediatrics Genetics/Metabolism Section and the National Kidney Foundation. These Young Investigator Awards attempt to interest talented medical professionals in research careers by providing the initial funding for their research.

Most recently, Sigma Tau joined with Children's National Medical Center and NORD to participate in a children's program entitled, "The Challenge of Treating Children With Chronic Illness."

In collaboration with the National Organization on Disability, Exceptional Parent is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

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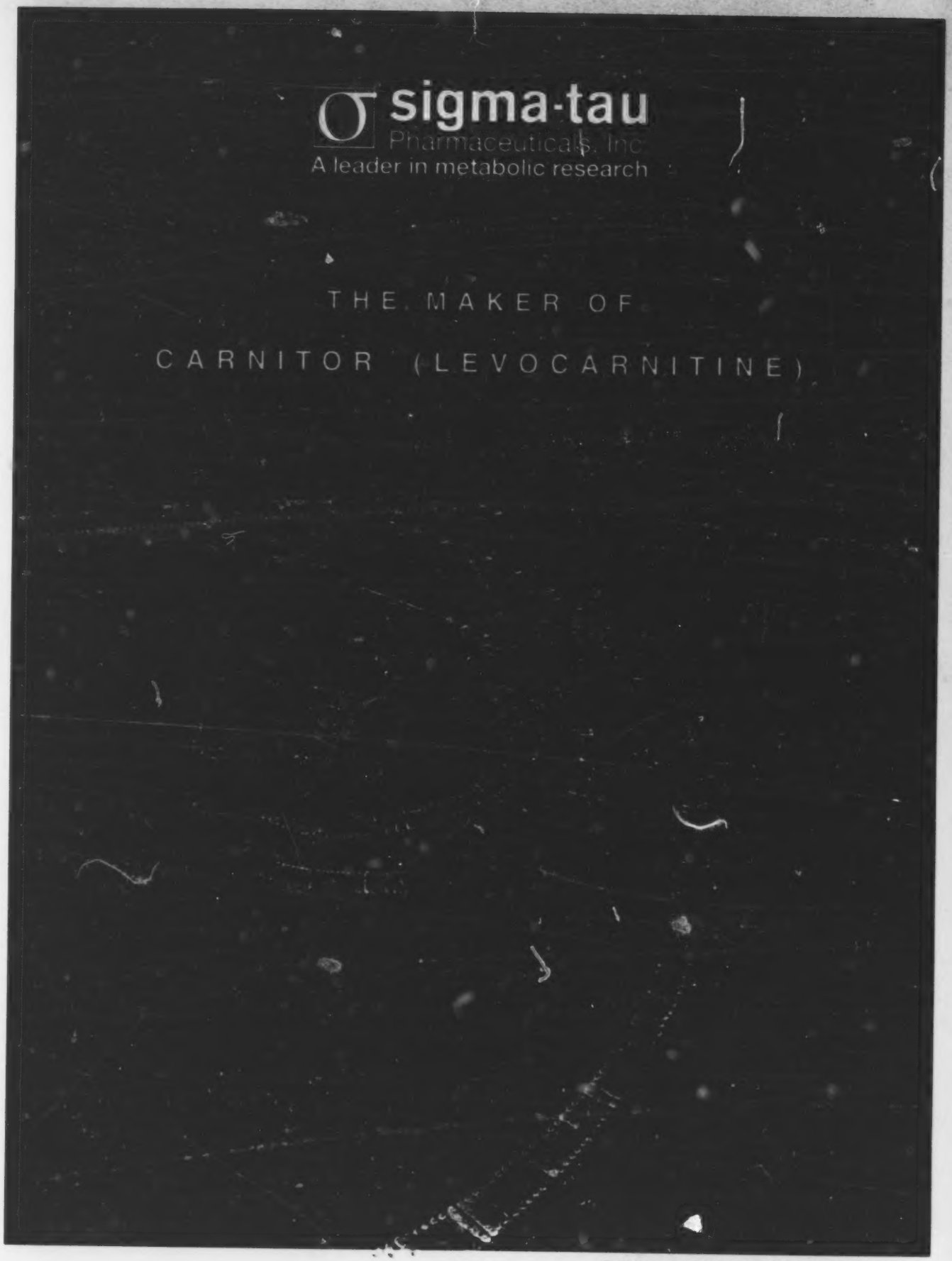

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Each 118 mL container of the CARNITOR® (Levocarnitine) Oral Solution contains 1 g of levocarnitine/10 mL. Also contains: Artificial Cherry Flavor, D&C Red No. 33, D,L-Malic Acid, FD&C Red No. 40, Purified Water, Sucrose Syrup. Methylparaben NF and Propylparaben NF are added as preservatives. The pH is approximately 5.

CARNITOR® (Levocarnitine) Injection is a sterile aqueous solution containing 1 gram of levocarnitine per 5 mL ampoule and 500 mg of levocarnitine per 2.5 mL ampoule. The pH is adjusted to 6.0 - 6.5 with hydrochloric acid.

Clinical pharmacology: CARNITOR® (Levocarnitine) is a naturally occurring substance required in mammalian energy metabolism. It has been shown to facilitate long-chain fatty acid entry into cellular mitochondria, therefore delivering substrate for oxidation and subsequent energy production. Fatty acids are utilized as an energy substrate in all tissues except the brain. In skeletal and cardiac muscle they serve as major fuel. Primary systemic carnitine deficiency is characterized by low plasma, RBC, and/or tissue levels. It has not been possible to determine which symptoms are due to carnitine deficiency and which are due to the underlying organic acidemia, as symptoms of both abnormalities may be expected to improve with carnitine. The literature reports that carnitine can promote the excretion of excess organic or fatty acids in patients with defects in fatty acid metabolism and/or specific organic acidopathies that bioaccumulate acyl-CoA esters.[1]

Secondary levocarnitine deficiency can be a consequence of inborn errors of metabolism. CARNITOR® may alleviate the metabolic abnormalities of patients with inborn errors that result in accumulation of toxic organic acids. Conditions for which this effect was demonstrated are: glutaric acidemia II, methyl malonic acidemia, propionic acidemia, and medium chain fatty acyl-CoA dehydrogenase deficiency.[2] Ammonia toxicity occurs in these patients due to the accumulations of acyl-CoA compounds that disrupt intermediary metabolism. The subsequent hydrolysis of the acyl CoA compound to its free acid results in acidosis that can be life threatening. Levocarnitine clears the acyl CoA compound by formation of acyl carnitine which is quickly excreted. Levocarnitine deficiency is defined biochemically as abnormally low plasma levels of free carnitine (less than 20 µM/L at age greater than one week past term) and may be associated with low tissue and/or urine levels. Further, this condition may be associated with a ratio of plasma ester/free levocarnitine levels greater than 0.4 or abnormally elevated levels of esterified levocarnitine in the urine. In premature infants and newborns, secondary deficiency is defined as plasma free levocarnitine levels below age related normal levels.

Bioavailability/Pharmacokinetics: In a relative bioavailability study in 15 healthy adult male volunteers CARNITOR® tablets were found to be bioequivalent to CARNITOR® Oral Solution. Following the administration of 1980 mg b.i.d. the maximum plasma concentration level (C_{max}) was 80 nmol/mL and the time to maximum concentration (T_{max}) occurred at 3.3 hours. There were no significant differences for AUC and urinary excretion observed between these two formulations.

In the same bioavailability study of 15 healthy adult males, CARNITOR® (Levocarnitine) Injection administered as a dose 3 minute bolus intravenous injection at a dose of 20 mg/kg showed that free levocarnitine plasma profiles are best fit by a two compartment model. Approximately 76% of free levocarnitine is eliminated in the urine. Using plasma levels uncorrected for endogenous levocarnitine, the mean distribution half life was 0.585 hours and the mean apparent terminal elimination half life was 17.4 hours following a single intravenous dose.

The absolute bioavailability of L-carnitine from CARNITOR® Tablets and Oral Solution was determined compared to the bioavailability of L-carnitine from CARNITOR® Injection administered intravenously in 15 healthy male volunteers. After correction for circulating endogenous levels of L-carnitine in the plasma, absolute bioavailability was 15.1% ± 5.3% for L-carnitine from CARNITOR® Tablets and 15.9% ± 4.9% from the Oral Solution.

Total body clearance of L-carnitine (Dose/AUC excluding endogenous baseline levels) was a mean of 4.00 L/hr. Endogenous baseline levels were not subtracted since total body clearance of L-carnitine does not distinguish between exogenous sources of L-carnitine and endogenously synthesized L-carnitine. Volume of distribution of the intravenously administered dose above baseline endogenous levels was calculated to be a mean of 29.0 L ± 7.1 L (approximately 0.39 L/kg) which is an underestimate of the true volume of distribution since plasma L-carnitine is known to equilibrate slowly with, for instance, muscle L-carnitine.

L-carnitine was not bound to plasma protein or albumin when tested at any concentration or with any species including the human.[3]

Metabolism and excretion: Five normal adult male volunteers, administered a dose of [^{3}H-methyl]- L-carnitine following 15 days of a high carnitine diet and additional carnitine supplement, excreted 58 - 65% of administered radioactive dose in 5 to 11 days in the urine and feces. Maximum concentration of [^{3}H-methyl]-L-carnitine in serum occurred from 2.0 to 4.5 hr after drug administration. Major metabolites found were trimethylamine N-oxide, primarily in urine (8% to 49% of the administered dose) and [^{3}H]-γ-butyrobetaine, primarily in feces (0.44% to 45% of the administered dose). Urinary excretion of carnitine was 4% to 8% of the dose. Fecal excretion of total carnitine was less than 1% of total carnitine excretion.[4]

After attainment of steady state following 4 days of oral administration of L-carnitine with CARNITOR® Tablets (1980 mg q12h) or Oral Solution (2000 mg q12h) to 15 healthy male volunteers, urinary excretion of L-carnitine was a mean of 2107 and 2339 µmoles, respectively, equivalent to 8.6% and 9.4%, respectively, of the orally administered doses (uncorrected for endogenous urinary excretion). After a single intravenous dose (20 mg/kg) prior to multiple oral doses, urinary excretion of L-carnitine was 6974 µmoles equivalent to 75.6% of the intravenously administered dose (uncorrected for endogenous urinary excretion).

Indications and usage: CARNITOR® (Levocarnitine) Tablets and Oral Solution are indicated in the treatment of primary systemic carnitine deficiency. In the reported cases, the clinical presentation consisted of recurrent episodes of Reye-like encephalopathy, hypoketotic hypoglycemia, and/or cardiomyopathy. Associated symptoms included hypotonia, muscle weakness and failure to thrive. A diagnosis of primary carnitine deficiency requires that serum, red cell and/or tissue carnitine levels be low and that the patient does not have a primary defect in fatty acid or organic acid oxidation (see Clinical Pharmacology). In some patients, particularly those presenting with cardiomyopathy, carnitine supplementation equally alleviated signs and symptoms. Treatment should include, in addition to carnitine, supportive and other therapy as indicated by the condition of the patient. CARNITOR® (Levocarnitine) Tablets and Oral Solution are also indicated for acute and chronic treatment of patients with an inborn error of metabolism that results in a secondary carnitine deficiency.

CARNITOR® (Levocarnitine) Injection is indicated for the acute and chronic treatment of patients with an inborn error of metabolism that results in secondary carnitine deficiency.

Contraindications: None known.

Warnings: None.

Precautions:
General: CARNITOR® (Levocarnitine) Oral Solution is for oral/internal use only. Not for parenteral use.

Gastrointestinal reactions may result from too rapid consumption of oral levocarnitine. CARNITOR® (Levocarnitine) Oral Solution may be consumed alone or dissolved in drinks or other liquid foods to reduce taste fatigue. It should be consumed slowly and doses should be spaced evenly throughout the day to maximize tolerance.

CARNITOR® (Levocarnitine) Injection is for intravenous use only.

Carcinogenesis, mutagenesis, impairment of fertility: Mutagenicity tests performed in Salmonella typhimurium, Saccharomyces cerevisiae, and Schizosaccharomyces pombe indicate that CARNITOR® (Levocarnitine) is not mutagenic. Long-term animal studies have not been conducted to evaluate the carcinogenic potential of the levocarnitine.

Pregnancy
Pregnancy Category B.: Reproductive studies have been performed in rats and rabbits at doses up to 3.8 times the human dose on the basis of surface area and have revealed no evidence of impaired fertility or harm to the fetus due to CARNITOR®. There are, however, no adequate and well controlled studies in pregnant women. Because animal reproduction studies are not always predictive of human response, this drug should be used during pregnancy only if clearly needed.

Nursing mothers: It is not known whether this drug is excreted in human milk. Because many drugs are excreted in human milk, a decision should be made whether to discontinue nursing or to discontinue the drug, taking into account the importance of the drug to the mother.

Pediatric uses: See Dosage and Administration.

Adverse reactions: Various mild gastrointestinal complaints have been reported during the long-term administration of L - or DL-carnitine; these include transient nausea and vomiting, abdominal cramps, and diarrhea. Less frequent adverse reactions are body odor, nausea, and gastritis. An occurrence like these reactions is difficult to estimate due to the confounding effects of the underlying pathology. Mild myasthenia has been described only in uremic patients receiving DL-carnitine.

Decreasing the dosage often diminishes or eliminates drug-related patient body odor or gastrointestinal symptoms when present. Tolerance should be monitored very closely during the first week of administration, and after any dosage increases. Gastrointestinal adverse reactions with CARNITOR® (Levocarnitine) Oral Solution dissolved in liquids might be avoided by a slow consumption of the solution or by a greater dilution.

Overdosage: There have been no reports of toxicity from carnitine overdosage. The oral LD_{50} of levocarnitine in mice is 19.2 g/kg. Carnitine may cause diarrhea. Overdosage should be treated with supportive care.

Dosage and administration: CARNITOR® (Levocarnitine) Tablets
Adults: The recommended oral dosage for adults is 990 mg two or three times a day using the 330 mg tablets, depending on clinical response.

Infants and children: The recommended oral dosage for infants and children is between 50 and 100 mg/kg/day in divided doses, with a maximum of 3 g/day. Dosage should begin at 50 mg/kg/day. The exact dosage will depend on clinical response.

Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations and overall clinical condition.

CARNITOR® (Levocarnitine) Oral Solution
For oral use only. Not for parenteral use.

Adults: The recommended dosage of levocarnitine is 1 to 3 g/day for a 50 kg subject which is equivalent to 10 to 30 mL/day of CARNITOR® (Levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 1 g/day, (10 mL/day), and be increased slowly while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

Infants and children: The recommended dosage of levocarnitine is 50 to 100 mg/kg/day, which is equivalent to 0.5 mL/kg/day CARNITOR® (Levocarnitine) Oral Solution. Higher doses should be administered only with caution and only where clinical and biochemical considerations make it seem likely that higher doses will be of benefit. Dosage should start at 50 mg/kg/day, and be increased slowly to a maximum of 3 g/day (30 mL/day) while assessing tolerance and therapeutic response. Monitoring should include periodic blood chemistries, vital signs, plasma carnitine concentrations, and overall clinical condition.

CARNITOR® (Levocarnitine) Oral Solution may be consumed alone or dissolved in drink or other liquid food. Dosage should be spaced evenly throughout the day (every three or four hours) preferable during or following meals and should be consumed slowly in order to maximize tolerance.

CARNITOR® (Levocarnitine) Injection. CARNITOR® Injection is administered intravenously. The recommended dose is 50 mg/kg given as a slow 2-3 minute bolus injection or by infusion. Often a loading dose is given to patients with severe metabolic crisis followed by an equivalent dose over the following 24 hours. It should be administered q24h or q48h, and never less than q48h either by infusion or by intravenous injection. All subsequent daily doses are recommended to be in the range of 50 mg/kg or as therapy may require. The highest dose administered has been 300 mg/kg.

It is recommended that a plasma carnitine level be obtained prior to beginning the parenteral therapy. Weekly and monthly monitoring is recommended as well. The monitoring should include blood chemistries, vital signs, plasma carnitine concentrations. The plasma free carnitine level should be between 35 and 60 nanomoles/liter and overall clinical condition. Parenteral drug products should be inspected visually for particulate matter and discoloration prior to administration, whenever solution and container permit.

Compatibility and Stability: Carnitor® Injection is compatible and stable when mixed in aseptated solutions of Sodium Chloride 0.9% or Lactated Ringer's in concentrations ranging from 250 mg/500 mL (0.5 mg/mL) to 4200 mg/500 mL (8.0 mg/mL) and stored at room temperature (25°C) for up to 24 hours in PVC plastic bags.

How supplied: CARNITOR® (Levocarnitine) Tablets are supplied as 330 mg (cent dose) tablets embossed with "CARNITOR 5-T" as individual blisters packaged in boxes of 90 (NDC 54482-144-07). Store at room temperature (25°C/77°F).

CARNITOR® (Levocarnitine) Oral Solution is supplied in 118 mL (4 fl. oz.) multiple-unit plastic containers. The multiple-unit containers are packaged 24 per case (NDC 54482-145-08). Store at room temperature (25°C/77°F). CARNITOR® (Levocarnitine) Oral Solution manufactured for: Sigma-Tau Pharmaceuticals, Inc. By: Diare-Kuhnard, Inc. Baltimore, MD 21207-3642.

CARNITOR® (Levocarnitine) Injection, 200 mg per 1 mL, is available in 5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-09) and 2.5 mL single dose ampoules packaged 5 ampoules per carton (NDC 54482-146-10). Made in Italy. Store ampoules at room temperature (25°C / 77°F) in carton until these use to protect from light. Discard unused portion of an opened ampoule, as they contain no preservative.

Caution: Federal (U.S.A.) law prohibits dispensing without prescription.

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Health

READERS TALK ABOUT:
Positive Experiences with Health Professionals

More Typical Than Not

"Devastated beyond words"—that's how I describe my reaction when, two years ago, our beautiful new daughter, Mackenzie, was diagnosed with Down syndrome. The information we were given at the hospital was neither overtly negative nor cruel. Still, it certainly gave us no reason to look forward enthusiastically to the future. Thankfully, I was referred to pediatrician Celia DiMarco for Mackenzie's well-baby care.

On our first visit, Dr. DiMarco welcomed my daughter as a beautiful newborn, emphasizing her positives: "Her lungs sound perfect... her heart sounds wonderful... her skin is lovely." The medical staff at the hospital had emphasized my daughter's "abnormalities." It was an enormous relief to hear words such as "perfect" describing my daughter.

Pediatrician Celia DiMarco (right) always reminds the Bockwoldts that two-year-old Mackenzie (above) is more a typical child than not.

Thanks to Dr. DiMarco, Down syndrome has not become the confining context of my daughter's life. She emphasizes that our daughter is an integral member of our family; that she will look and act like us. When my daughter's various childhood ailments are *not* related to Down syndrome, Dr. DiMarco is quick to point this out, emphasizing what Mackenzie has in common with *all* her other patients of the same age. At the same time, she is constantly relaying the accomplishments of her other patients with Down syndrome.

Dr. DiMarco's continuing enthusiasm and optimism is vital to our family. Her encouragement is with us always, reminding us that our daughter is more a typical child than not.

—Denise Bockwoldt
Clearwater, Florida

A Heart-shaped Bandage

Growing fat and healthy: Eric Allen relaxes with a good book after surgery to correct severe gastroesophageal reflux.

When Eric's gastroesophageal reflux got to the point where he could no longer keep food in his stomach, our son's pediatrician referred us to a surgeon. My husband and I had had enough experience with the medical profession to assume we would again be subjected to inadequate treatment and impersonal bedside manners. But, to our surprise, we were introduced to a surgeon who was compassionate, devoted, intelligent and showed an outstanding dedication to his patients and their families: Dr. John Aiken.

When Dr. Aiken explained the surgical procedure Eric needed, he did so in such great detail that I couldn't help but feel extremely confident. He was always accessible—even giving us his home telephone number. Not only did he see Eric when he was on call, he also visited our son on his weekends off—often with his three-year-old son in tow.

Dr. Aiken included us in the decision-making process, using our observations and knowledge to plan Eric's treatment. Eric returned from his surgery with a heart-shaped bandage over the incision. A nurse told us that was Dr. Aiken's trademark.

Eric's surgery took place during the holidays, just as we moved into a new house and at the same time that my father suffered a stroke. I worked full-time, and divided the rest of the time between my father and Eric, in two different hospitals 85 miles apart. It may sound like a nightmare, but I actually recall that time fondly. Perhaps that's because my son is now growing fat and healthy, or because my father is recovering rapidly; but I attribute a large part of my positive memories to the fact that we were in the hands of a caring, respectable, humane physician who, I'm convinced, saved my son's life.

—Ann Allen
Oshkosh, Wisconsin

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Going the Extra Mile

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Our daughter, Jerri, was born with osteogenesis imperfecta (OI), a condition characterized by fragile bones that break easily. She arrived by C-section with broken arms and legs, a broken collarbone, no kneecaps, a twisted left leg and many broken ribs. When she was two months old, we were referred to Dr. Patrick Barrett and his nurse, Gelinda, who is also his wife. I will never forget the compassion on their faces the first time we met. When our son Robby was born, also with OI, they assumed his care as naturally as they had Jerri's.

Jerri, now 15, has had more than 300 broken bones; Robby, 8, has had more than 100. Our children's bones break so easily—just by riding in a car or lifting a leg. During surgery, their bones have actually crumbled in the doctor's hands.

The Barrett team has always gone that extra mile—sometimes quite literally—to give our children not only great medical care, but also comfort and joy. When Jerri's neck broke, they arranged a pizza party in her hospital room—and Chuck E. Cheese delivered the pizza and sodas!

Because even the most careful surgical nurses could break our children's bones by moving them improperly, Gelinda has accompanied Jerri through her many surgeries. She takes Jerri in her arms at the operating room door and watches over her until she is asleep. When Robby had surgery this past December, Gelinda was there for him as well.

Dr. Patrick Barrett and his nurse (and wife), Gelinda Barrett, have cared for Jerri Hodge (second from left) since the age of two months, and Robby Hodge (far right) since birth. "People sometimes wonder why we drive two hours one way to see a doctor," writes their mother, Darlene. "I always reply that I would drive farther than that to see someone I can trust with my children."

We have thanked these special people over and over. Still, they will never know how much they have helped us. They've not only cared for our children's bodies, but they've put their minds—and ours—at ease.

—Darlene Hodge
Laurel, Mississippi

Welcoming Rory With Joy

A few hours after Rory's birth in June 1994 at Brigham and Women's Hospital in Boston, the doctor gently and honestly told us that he suspected our new son had Down syndrome. About 48 hours later, these suspicions were confirmed.

From the moment of Rory's birth, until we left for home three days later, the doctors, nurses and staff of both the hospital and our health maintenance organization—Harvard Community Health Plan (HCHP)—treated us with sensitivity and warmth. The fact that Rory had trisomy 21 meant many serious—sometimes scary—discussions with various medical professionals. But despite their serious nature, *every* conversation began with congratulations. Every professional we encountered treated us as the happy new parents of a beautiful little boy—exactly what we were! Our learning process was made easier by this positive and straightforward approach and the additional specialized support from our health plan. HCHP has a Down syndrome program that is run by Suzanne Morse Fortier, the mother of a fantastic young lady, Lucy, who has Down syndrome. We'll always remember Suzanne's message: "The sky's the limit." Every new parent dreams of the things that their child will accomplish. She told us we should be no different.

Rory Callaghan is supported by a team of caring medical professionals at Harvard Community Health Plan, including (from left) pediatrician John Taub, M.D., ENT Michael Williams, M.D., and speech therapist Jennifer Johnson, M.S.

We have continued to be impressed with the care we receive from HCHP. The plan's Down syndrome program offers access to information, monthly seminars and opportunities to meet

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other parents. Our managed care plan also provides us with access to an array of medical specialists. Besides Rory's pediatrician, Dr. John Taub, he has the additional support of a developmental team headed by Dr. David Pangburn. This team coordinates all Rory's tests and evaluations and determines the developmental support he needs.

The positive support we received in the first days of Rory's life built a foundation that allowed us to deal very positively with his diagnosis. With this base, with the support of family and friends and, most of all, with the magic that Rory brought to our life, we were able to welcome him with the joy he deserved and to focus on the positive.

—Francis and Gillian Callaghan
Wellesley, Massachusetts

More Than a Health Care Provider

We met physical therapist Ann Robertson when our daughter, Kabria Germaine, was about four months old. Kabria had experienced hemorrhaging on the left side of her brain shortly before birth. Her official diagnosis is cerebral palsy with microcephaly. Now 3, Kabria functions between the 12- and 18-month level developmentally.

Ann manages physical and occupational therapy services at Grady Memorial Hospital in Atlanta. Kabria's developmental pediatrician, who referred us to Grady's Developmental Continuity Clinic, was worried about our reaction to being referred to a public hospital that had a somewhat negative reputation. But, he explained, Grady offered one huge benefit we couldn't find anywhere else—Ann Robertson. The doctor told us Ann was the best physical therapist around, and we replied, "Then, we're going to Grady!" (We've since found that Grady's negative image is largely undeserved. In fact, because Grady is a teaching hospital that serves a large and diverse population, it offers many of the best and brightest minds in the medical profession.)

Kabria Savage, 3, attends the Easter Seal Children's Center in Atlanta, Georgia. "It was Ann who pushed us to consider options for Kabria other than daycare—actual educational options," explains her mother, Kim.

From day one, Ann never looked at Kabria simply as a physical therapy "patient," but looked at all aspects of Kabria's development. She considered not only what Kabria was doing at the moment, but also offered advice and encouragement about her future. It was Ann who recommended occupational therapy. It was Ann who noticed that something was wrong with Kabria's vision. It was Ann who told us when the time was right for speech and language services. And it was Ann who pushed us to consider options for Kabria other than daycare—actual educational options.

Ann taught me that if you work hard and consistently, great results will come in time. It was a hard lesson to learn. Ann consistently pushed Kabria to do her best, recognizing that our daughter—like her mother—has a strong-willed personality and was determined to do the minimum asked of her. I was furious the first time Ann made "my baby" cry! But thanks to Ann's vision and persistence, Kabria sat unsupported at 11 months of age, pulled up to a sitting position by the time she was two, and, shortly thereafter, increased her mobility by learning to roll around and scoot on her backside.

It's been more than a year since Kabria has been Ann's regular patient. Ann is still our consultant and confidant, however, working closely with Kabria's current therapists and teachers. Thanks to Ann's prodding, Kabria's new physical therapist agreed to allow Kabria to begin using a walker—and she now walks independently. Ann also helped us obtain an augmentative communication evaluation when few other professionals believed Kabria was ready—and we're now working on finding funding for the communication device that was recommended.

Whenever I become depressed and don't see results as quickly as I'd like to see them, I call Ann. She reassures me that we have done a remarkable job with Kabria and are continuing to do everything right. My husband, James, and I no longer consider Ann a health care provider. She is a personal family friend.

—Kim Savage
Douglasville, Georgia

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of Exceptional Parent:

- **Making connections through Exceptional Parent:** We know people find each other all the time through this magazine—through the annual Resource Guide, through articles; through *Search, Respond* and *Letters;* even through *Familiar Faces.* Here's a chance to share *your* "connection" story. (November issue; deadline September 1)
- **When your child grows up:** Where will he or she live, and with whom? Share your dreams, plans and concerns. (December issue; deadline October 1)

Write to: Readers Talk, Exceptional Parent, 209 Harvard St., Ste. 303, Brookline, MA 02146. (617) 730-8742 (fax)

Health

Delivering Difficult News

by Stanley D. Klein and Kim Schive

Many professionals view parents as nervous, guilty, anxious, depressed and/or overprotective. Such perspectives may have their roots in observations of parents in health care settings or educational meetings—times when parents are under significant stress. Unfortunately, after observing many parents under the stress of seeking help for a child with a "problem," professionals can conclude that *all* parents are *always* anxious and troubled.

Despite increasing evidence to the contrary, this erroneous belief is often reinforced by the media and some professional literature, both of which continue to blame parents, especially mothers, for children's physical disabilities and mental illnesses. The unfortunate result of such experiences in the lives of developing professionals is that many unwittingly carry negative stereotypes into their encounters with parents. These prejudices interfere with professionals' perceptions and ability to communicate constructively. These negative stereotypes will be broken down only when open-minded professionals are given opportunities to discuss their perceptions and attitudes with parents.

Parents = experts and partners

Professionals need to appreciate that parents are experts about their own child and can serve as teachers to professionals. Parents can also be partners in the process of diagnosis and treatment. However, rather than viewing mothers of children with disabilities as experts, professionals have misperceived them as hostile, demanding and probably psychopathological. But speaking out on behalf of the needs of loved ones is far from psychopathological; recent studies of female development make it clear that such behavior is a way for women to assert themselves in a healthy, appropriate fashion.

Techniques for successful collaboration

Setting: It is usually important for professionals to meet with parents separate from the child. Meetings should be scheduled for a time that is convenient for the parents, and with the understanding that the conversation can be continued at a second meeting. Participants will be more likely to engage in active give and take when: 1) each participant is seated in an equally comfortable chair; 2) all are at the same eye level; 3) each is seated at a conversational distance from others; and 4) each can take notes comfortably.

Thus, a separate room or seating area with a desk or table and adult-sized chairs is more appropriate than using a medical examining room or a room with furniture designed for young children. In addition, a separate setting provides the uninterrupted privacy parents need and deserve.

Including Dad: Some professionals always seem to expect mothers to attend meetings—as though they are at home with nothing better to do. At the same time, professionals often convey the unspoken message that fathers need not attend, because they are not involved enough anyway. Including fathers may require a special invitation. Not only does such an invitation counteract common male parenting patterns, it also communicates the view that Dad has an important role. Even divorced fathers without custody can participate.

Number of professionals? Sometimes information is presented to parents at a "team" meeting in which each professional involved has a turn presenting the findings in a particular area. In medical teaching settings, an "entourage" of medical students may attend. Some school systems convene team meetings because they believe that such meetings are mandated by Federal law; in fact, the law requires only that three professionals attend meetings with parents at which individualized education plans (IEPs) are created.

Not surprisingly, most parents report feeling overwhelmed when the number of professionals exceeds the number of parents! I believe that meetings including many professionals discourage parental participation and can contribute to a disorganized approach to the child and family. Meetings with one or two key professionals are usually preferable. One of the professionals present should be the person who will be involved in follow-up communications with the parents. Some parents also find the participation of a trained parent advocate very helpful.

Considering emotional impact

Communicating that a child has a "problem" is a challenging responsibility. No professional can make sad news sound like good news. Instead, the professionals can provide an opportunity for parents to begin the difficult process of mourning the loss of the "perfect" child they had anticipated and get on with the job of parenting the child they have.

For some professionals, delivering sad news to parents is an everyday, relatively routine, task. In dramatic contrast, the moment of hearing that news for the first time is an experience parents will never forget. The memories formed in those few moments will be painfully reviewed again and again in the years to come. This encounter can influence the perceptions of professionals that parents carry into the future—sometimes in negative, irreparable ways.

Because of the emotional impact of this meeting, professionals must approach it with compassion and an appreciation that delivering sad news in an appropriate manner takes time. Sad news cannot be constructively presented by a professional who is standing with one hand on the doorknob, poised to go on to the next "case." It requires a step-by-step discussion with everyone seated—and a readily available box of tissues.

Professionals always need to speak in understandable language. Few people—even the most well-educated—

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A Letter to Doctor X

Last summer, I participated in a Parent/Professional Communication in San Antonio, Texas. The seminar was a session, led by EXCEPTIONAL PARENT *editor-in-chief Stanley Klein, in which health care professionals and parents of children with disabilities discussed the manner in which professionals present diagnoses to parents.*

During the seminar, one man expressed a lot of anger about the uncaring manner of the doctor who had initially diagnosed his child. I suggested he put those feelings into writing with a letter to the doctor; regardless of whether he sent it or not, it would help him work through his anger. When I got home, I realized I, too, was harboring anger toward the ophthalmologist who had offered little comfort or support when he incorrectly diagnosed my daughter, Madison, with blindness. I decided to take my own advice, and wrote the ophthalmologist a letter, an adaptation of which is printed here. I don't expect a reply from the doctor, but it did make me feel better to put the words on paper.

—D. Alison Rickerl
Houston, Texas

The Rickerl family—Ted, Alison, Meglyn Rebecca, 3, and Madison Celeste, 17 months—pose for a picture with Santa at the Texas Commission for the Blind Parents' Network Christmas Party in 1995. Alison writes, "The hardest thing is getting Madison to look at a camera she can't see!"

Dear Dr. X,

It has been almost a year since you told us our daughter, Madison, was "essentially blind." I remember seeing the look of pity on your face and watching as you turned around and muttered something to Dr. Z.—I realized later that you had said, "optic nerve hypoplasia." Madison's actual diagnosis. *[EDITOR'S NOTE: Optic nerve hypoplasia (ONH) is a congenital condition in which the optic nerve fibers are underdeveloped, causing visual impairment.]* You told us, "Go back to your pediatrician to find out what else is wrong." You said you would dictate a letter to our pediatrician, and then you left.

Dr. Z stayed with us for a while, offered some words of sympathy and told us to call him anytime with questions. On our way out, even as the tears streamed down my face, your receptionist coldly asked for our money. No one offered information on where to get help or what to do next.

A painful time

I called back a few days later to talk to your colleagues, Dr. Z and Q, who were kind and somewhat informative. Q even sent a list of abstracts from research papers on ONH. Eventually, someone from your office also sent a short list of resources.

Each time I made a phone call, I had to explain, "I have a baby who was just diagnosed as blind, and I don't know what to do. Can you help me?" Invariably, the person would pause, put me on hold, and then transfer me to someone else for whom I would have to repeat my painful story.

My brother-in-law, Sam, who was interning as an obstetrician/gynecologist, took some time to research Madison's diagnosis, fax us some information and explain some of the medical terms. Our pediatrician used the information Sam had collected to decide on additional evaluations that should be run. Your memo to Madison's pediatrician was not helpful.

Eventually, we took Madison to see an endocrinologist and to have a magnetic resonance imaging (MRI) scan. Madison's veins are very hard to find, and she suffered a great deal when her blood was drawn for the tests. She was sedated with a "pedi-cocktail" for the MRI, but during the test, her heart rate dropped and she had to be admitted to the hospital.

A turn of events

Through contacts with other parents, I found out about Dr. V, a physician in California who was conducting an ONH research study. After speaking with him, we decided to include Madison. We brought her to Los Angeles, where Dr. V conducted several tests. When the procedures were over, Dr. V showed us the results, explained them in detail and spent time answering our questions until we were satisfied.

His most significant finding was that Madison did not have ONH—she had foveal hypoplasia. *[EDITOR'S NOTE: Foveal hypoplasia is an underdevelopment of the area of the retina responsible for the sharpest vision.]* Madison is not "essentially blind;" she has a major visual impairment, which has improved dramatically. Dr. V's report states that Madison's optic nerves, although "slightly small," are within normal limits. I have enclosed a complete copy of his report.

Madison can reach for objects accurately and track toys and faces up to three feet away. Her gross motor skills are significantly delayed, but her fine motor skills are almost right on target. She is healthy, smart and happy.

I believe your incorrect diagnosis and your failure to provide us with any information about ONH or helpful services put us through more grief than was necessary. The diagnosis would have been easier to deal with if we'd had all the information we needed.

Some suggestions

Here are some things you can do so other parents will not have to go through the same traumatic experiences as us:

- Spend time with the parents. Give them a chance to absorb the diagnosis. Let them sit and cry and pull themselves together before they have to drive home and tell their families the news.
- Provide information about the child's diagnosis right away—preferably written information so the parents can take it with them.
- Give parents the opportunity to ask questions, and answer those questions fully. Do not let them walk out of your office if they are obviously distressed.
- Do not let parents leave without the names and phone numbers of support groups and intervention services. Better yet, have your receptionist make the initial phone calls to get the parents started. If you cannot do these things, hire a child life specialist to help.

Children who are blind or have visual impairments need immediate help if they are to grow into self-supporting, productive members of society. I believe that professionals who diagnose visual impairments are partly responsible for ensuring that parents know where to get the help they need to make this happen. Please consider it.

Sincerely,

D. Alison Rickerl

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understand technical medical and educational terminology.

Step by step

A thoughtful, step-by-step manner of presenting difficult news takes into account parents' predictable shock and distress and provides appropriate educational information. The time to begin preparing parents for the possible, eventual presentation of difficult news is during the "history"—the initial meeting that occurs prior to an evaluation for the purpose of reviewing known, relevant facts about the child's condition. Professionals can actively involve parents in this process by asking for their observations of the child's development in the areas (for example, hearing, language, motor skills or memory) that the team will be evaluating. Professionals can also ask parents to talk about their goals for the evaluation process.

The meeting in which the difficult news is to be delivered can begin with a review of the parents' observations and concerns. This can be followed by the professionals' observations, which confirm or further clarify those of the parents. Then, the professional can gradually move on to the diagnosis and prognosis by taking parents "inside" the child's body to explain the relationships between internal processes and observable behaviors in understandable, everyday language.

Finally, professionals must present the difficult news using specific diagnostic terminology. Because some professionals want to "protect" parents from the distress associated with these terms, they may postpone using specific terminology or rely on euphemisms. However, since parents are usually worried and aware that something is amiss, avoidance of diagnostic terms is not helpful; it only leaves parents fearful and uncertain.

In fact, knowledge of specific diagnostic terminology empowers parents to learn and grow in three ways. First, by speaking openly about the diagnosis, professionals and parents can discuss possible future problems and means of coping. Second, knowledge of diagnostic terms gives parents access to educational materials. Third, since local and national support groups are usually organized according to specific diagnoses, diagnostic information allows parents to benefit from the resources these groups provide.

Professionals must take time to listen to parents' reactions, worries and fears. Diagnostic terminology is loaded with emotion and mystery. Professionals can validate parental worries and present further explanations if needed.

Acknowledging parental distress

When faced with the information that a child has a disability or serious illness, the mature, mentally healthy parent will be very upset. Such distress is an understandable, healthy reaction. Unfortunately, some believe that parents' emotional distress is not a relevant subject for discussion and that the "healthy" reaction is to suppress feelings and "be strong."

Nothing could be further from the truth. Keeping difficult feelings inside consumes a great deal of energy. A parent who is working hard to suppress feelings and worries has very little energy available to pay attention to and learn the vital information the professional can provide.

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At this point, it can be useful to give parents explicit "permission" to be frightened and upset. It is useful to say something like, "[diagnostic term] is a frightening term," or "It's OK to cry." These statements make it clear that it is a normal, human reaction to be frightened by technical terminology that suggests a problem. Without this permission to be frightened, a parent may feel embarrassed by the way he or she feels, silently suppressing such feelings and pretending to understand when, in fact, he or she is unable to pay attention.

This critical step of acknowledging parents' emotional reactions gives parents the opportunity to talk about their shock, fear, sadness, even anger at the professional for providing the diagnosis. Agitation, confusion, anger and/or questioning behavior (such as repetitive questions about the diagnosis) are all signs of being upset and are part of the mourning process; they are not hostility or signs of parental "dysfunction."

It helps if the professional can say, "I appreciate how frightening it is to hear this news," or "I can appreciate that you must have all kinds of feelings, including very angry feelings, about this news." Comments like these validate parental emotions and explain that strong feelings are permissible and acceptable. Parents need to hear that—under the circumstances—it is normal to have many feelings at the same time. Parents also need to know that the professional is willing to listen patiently and will not criticize any emotional reactions.

After parents describe their feelings, the professional can gradually provide the educational information parents need to understand the diagnosis and to begin to meet the current needs of the child and the family.

Parents need to know that they are likely to experience a wide range of emotions because they will be going through a mourning process—mourning the loss of the child of their dreams. Giving lip service to such a mourning process does not bring it to an end. It takes time—time during which parents will need continued attention and concern.

Denial and anger

Denial is a human reaction to being upset and anxious. When professionals push harder to make a point that a parent seems to deny, the parent's anxiety will increase—further increasing denial. A more effective technique is to address the cause of the denial by acknowledging that the news is frightening and upsetting.

By specifically encouraging parents to talk about feelings of anger, professionals help prevent the clinical depression that may occur as parents try to cope with the birth or initial diagnosis of a child with a disability. In part, depression can be the result of a process that begins by turning angry feelings inward because there is no opportunity to express them.

The professional can also help by explaining the value of parents sharing the wide range of intense feelings each is likely to experience with each other—including the feeling of "going crazy." Parents need to know that these feelings are part of the mourning process, and that it will be helpful to speak openly with their loved ones, as well as with caring professionals. To prepare parents to be understanding and supportive of each

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other, it is also helpful to be remind them that individuals who are in mourning can severely test the patience of loved ones by speaking or behaving in troubling ways.

Information dosages

Sometimes, professionals feel upset themselves when parents are obviously distressed. The professional may cope with this personal discomfort (and believe he or she is meeting parental needs for information) by immediately presenting a thoughtful "lecture." Professionals may assume that the valuable information conveyed will help parents understand the child's condition and feel better. Instead, parents suffer through these lectures quietly and say little—even when asked if they have "any questions." They feel embarrassed about being upset, and further embarrassed for failing to understand the "lecture."

Parental questioning can sometimes provoke other unproductive professional behavior—especially when the professional isn't sure how to respond because the answer is unclear or unknown. In such situations, the professional can begin by acknowledging the validity of the concern expressed, and then say, "I don't know," or "I'm not sure," before suggesting a way for parents and professionals to work together to find answers.

Although parents need a great deal of information, the professional must consider the issues of dosage and timing. I am not aware of any specific "prescriptions" of information dosages for specific diagnostic conditions—especially during the stress of an initial discussion. Rather, it seems more useful to appreciate that parental needs for information are likely to change as the family confronts different challenges in different settings and stages of their lives. At the initial meeting, while validating parental concerns about the future, it is important to keep the focus on information the parent needs at that time.

Many parents of children with disabilities and/or special health care needs first hear the diagnostic news from professionals who will not be directly involved in the child's future care. It is essential that the primary care professional (or team) be given as much information as possible about the interaction between parents and professionals during the presentation of the diagnostic news. This will allow the primary care team to provide for continuing parental needs.

Support groups

The professional team needs to explain that parent support groups can provide emotional support and practical information very effectively, often far more effectively than any professional. By participating in such groups, parents can end feelings of isolation, share their grief and learn practical solutions to everyday challenges.

To connect parents with such groups, professionals need to be knowledgeable about appropriate local and national organizations. Professionals may be asking too much when they expect the distraught parents of a newly diagnosed child to have the energy and courage to contact a group of strangers. Rather, with permission, the professional can arrange for the group to reach out to the "new" parents.

Written reports

Even under the best of circumstances, well-intentioned, intelligent parents are unlikely to remember everything communicated verbally. While it can be helpful to take notes or make tape recordings, it is more effective if the professional explains that because it is very difficult to remember all that has been discussed, a written report will be prepared, using language understandable to lay persons, which summarizes the discussion in the meeting. This report will include the observations, the diagnosis and specific recommendations. Besides helping everyone remember what transpired during a particular meeting, such reports are valuable for other professionals who will be involved with the child and family but may be unfamiliar with the specific technical language professionals in the same specialty use when talking to each other. **EP**

Stanley D. Klein, Ph.D., is co-founder and editor-in-chief of Exceptional Parent. *He frequently speaks to audiences of parents and professionals on the topic of delivering difficult news. Kim Schive is the associate editor of* Exceptional Parent. *This article was adapted from a chapter that appears in* Families, Physicians, and Children with Special Health Care Needs: Collaborative Medical Education Models. *Readers are encouraged to share this article with health care professionals and educators.*

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I Am Tamra's Father

by Bob Miyamoto

Through the neurofibromatosis support group in Washington state, Tamra Miyamoto, 9, (right) has made friends with a number of other children who have NF.

I was a reluctant father, one who feared the responsibilities and diapers of those whirlwinds we call kids. Nine years had passed in our marriage, when the biological clock finally shattered our peaceful, kidless existence.

My first view of Tamra was a spinning pair of legs and a rotating tush. Her head was too big for the Cesarean incision and wouldn't come out! After much tugging by the doctor, she finally decided to join us. The pediatrician and I carefully counted toes, fingers, eyes and limbs. Excluding some slight, spotty skin discolorations, she looked perfect!

I would like to report that life returned to normal, but, as all parents discover, there is nothing normal about life after kids. Still, I was excited—even about changing diapers.

Being proper parents, my wife, Deanna, and I would accompany Tamra each month to her "well-baby" examinations and ask the pediatrician a thousand stupid questions. Each month, Tamra was pronounced to be in excellent health, but the pediatrician would frown at the spots on her skin. "Nothing to be concerned about yet," she would say, "but let's keep an eye on those."

Wait a minute, what does she mean by "yet?"

Leah, 4, and Tamra, 8, smile and squeal as their father, Bob, gives them their share of tickles.

Finding out about the spots

When Tamra was six months old, we brought her to a dermatologist-geneticist. It was time to find out about those spots. We waited nervously as the dermatologist carefully examined Tamra. That done, the doctor turned to us, and sternly asked us to remove our clothes. *Remove our clothes?* Shocked into silence and praying that I had worn some semblance of clean underwear, I did as I was told. After our examinations, we dressed and waited in silence.

The doctor told us that Tamra's skin discolorations were called cafe au lait spots, because they are the color of milk and coffee. They were an indication that Tamra had neurofibromatosis, more commonly called NF. Can you pronounce it? We couldn't. The doctor explained that NF is a dominant genetic disorder, but since Deanna and I showed no signs of the disease, Tamra's condition was a spontaneous genetic mutation.

NF is one of the most common genetic disorders, the doctor explained, occurring in one out of 4,000 newborns. Half of those cases are, like Tamra's, the result of a new mutation. People with NF develop tumors—called neurofibromas—of the central nervous system, nerves (including the auditory and optic nerves) and skin. The tumors are usually benign, but may be removed if they are painful or press on other body structures. The doctor continued with a list of other possible problems—bone deformations, learning disabilities, high blood pressure and itching.

My hearing seemed to turn off after a while, but it awakened to the doctor saying, "...used to be known as the Elephant Man's disease."

Back up a minute—"Elephant's Man's disease?" I asked.

The dermatologist explained that for a long time NF had been associated with Joseph Merrick, the so-called Elephant Man, but it had been recently discovered that Merrick's condition was Proteus syndrome, not NF.

What are the odds?

I couldn't have identified my emotions at this point; it was as if everything inside of me had gone

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(left to right) Bob, Tamra, 8, Leah, 4, and Deanna Miyamoto practice their synchronized fireplace-sitting routine.

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dead. We listened to the doctor further explain that many people with NF have no significant health problems, and go on to have careers and families.

The doctor told us that the odds were that Tamra would not have significant problems. But what did odds mean at that point? I mean, what were the odds of us having a child with NF in the first place?

Indeed, a few weeks later, we brought Tamra back to the dermatologist with a mumps-like swelling under her left jaw. Surgery to ensure that the tumor was benign confirmed neurofibromas on her facial nerve, which couldn't be removed without causing facial paralysis. What else did the future have to offer?

Running away

Work became just a way to pass the time. I shut out my fellow workers, conserving my energy to put on a brave face for my family at home. I burned off my anger and fear by putting on my running shoes and running as far and as fast as I could—which was neither very fast, nor very far. I learned that nobody can tell whether runners are happy or sad; mostly they just look tired, which I was. I came home drained, but sufficiently free to present an optimistic face to my family.

After a child is diagnosed with a disability, it seems fathers often act as if nothing is wrong, while mothers act

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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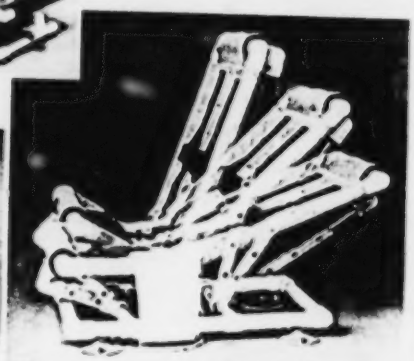

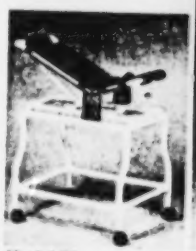

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as if their world has come apart. But eventually, most parents come together in attitude. The mother realizes that there can be life with the disability, and the father realizes that the disability exists.

I, too, had to face my anger and fear. I thought about what life was like before Tamra's diagnosis, and I asked myself what had changed the day the doctor gave us a name for her condition. Tamra hadn't changed—she had always had NF; I just didn't know it. So what had changed? I had.

Controlling what we can

I feared the uncertainty of the future. I knew there was nothing we could do to prevent Tamra's tumors; we could only react to them once they appeared. I felt powerless.

For two weeks after Tamra was diagnosed with NF, I couldn't stop crying. Then I returned to the basics—got the facts, educated myself, prepared. I learned to enjoy life again; I did not ignore Tamra's condition, but I also didn't let the fear of it dominate my life. It has been a long, eight-year struggle. I had to learn that NF will not go away and that I will survive.

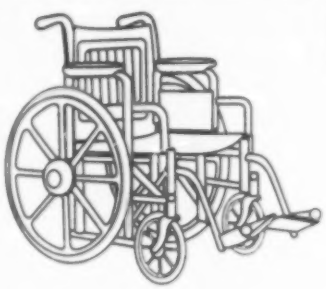
I've also come to believe that the best-adjusted adults with disabilities come from supportive families. This is something my wife and I *can* control. We believe that our daughter's attitude toward life will be a reflection of our own. No matter what happens, we try to overcome problems as a family. Tamra's self-confidence reflects our conscious decision not to fear NF.

Continuing the marathon

Rather than suffer from hopelessness, we've redirected our energy and much of our free time into working with our local NF chapter. I treat NF as a marathon—one foot in front of the other, one day at a time.

In many ways, my life has become richer because of Tamra's NF. It would have been easy to spend my time and energy pursuing the American dream of the greenest lawn, the cleanest car and the most toys. Now, my rewards are different—the smile of a child selling lemonade to support NF research, the handshake of a parent who needed to talk, and the knowledge that, no matter how small our successes, we've fought hard. **EP**

Bob Miyamoto is a research physicist and oceanographer at the Applied Physics Laboratory at the University of Washington. His wife, Deanna, is an art director at Image Ink Design Studio. The Miyamotos live in Bothell, Washington, north of Seattle, with their daughters, Tamra, 10, and Leah, 5. The Miyamotos are very active in the Washington state chapter of the National Neurofibromatosis Foundation; Bob served as chapter president from 1990 to 1994; he is currently the chapter's vice president. The family also enjoys swimming, skiing and hiking.



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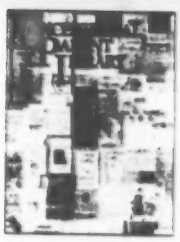

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RECREATION

Cerebral Palsy and Sports

Athletes ask, "Who says we can't?"

by Jan Little with Deborah Gaebler-Spira

Not too many years ago, if an individual with cerebral palsy was involved with an elite sports team for athletes with disabilities, it was as manager, statistician or other assistant to the athletes. A number of factors combined to prevent most people with cerebral palsy from actually competing. Not the least of these was the commonly held belief that individuals with cerebral palsy were particularly fragile and prone to injury. Medical professionals were especially concerned with the possibility that strength training might exacerbate already-existing spasticity, or muscle tightness. And few even considered the possibility of athletic participation by individuals with athetosis, a less common type of cerebral palsy characterized by a lack of controlled movement. However, there is no record of any medical researcher asking people with cerebral palsy for *their* opinion.

Athletes speak for themselves

In 1992, a survey of top athletes with cerebral palsy was completed by 36 elite athletes competing in the 1992 Paralympics in Barcelona, Spain. The survey asked open-ended questions about motivation, training, injuries and factors that had positively or negatively affected the athletes' participation and success in competitive athletics. The answers illuminated some of the unique obstacles faced by top athletes with cerebral palsy; however, they said even more about the ways in which these athletes are similar to their peers without disabilities.

• **Motivation:** Answers to the survey indicated that elite athletes with cerebral palsy train and compete for many of the same reasons as top athletes without disabilities. Respondents mentioned the enjoyment of meeting new people and seeing new places. Some talked about the excitement of competition and the thrill of winning. But, above all, they talked about the joy of mastery and the satisfaction of setting a goal and achieving it:

"I used to read about and watch the Olympics… my dream was to compete in track and field and cycling… if you have a dream, you get involved and work for it," said one athlete.

"I wanted to prove to myself and others… that disabilities shouldn't stop someone from succeeding and winning."

Jon McCullough, a Paralympic soccer player, conducts a soccer clinic at the 1996 United States Cerebral Palsy Athletic Association Youth Nationals.

• **Physical education classes:** More than half of the survey respondents reported receiving no encouragement at all from physical education teachers in school. Several referred to their physical education classes as "a joke." Others reported being excluded from classes entirely or being given the role of teacher's assistant. "School PE classes made me think I couldn't be an athlete," reported one athlete. "I wasn't exposed to wheelchair athletics until college."

But when a physical education teacher did make the effort to be encouraging, it often had an extremely positive impact. One top athlete with cerebral palsy attributes his entry into competitive sports at least partially to a third-grade gym teacher who "got after me to lose some of my baby fat."

• **Parents and siblings:** Most of these top athletes had parents and siblings who either supported them enthusiastically or, at least, did not discourage their interest in sports. Family support was especially important to athletes who received little support for their endeavors—

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PHOTOS COURTESY OF THE VIRGINIA WIRTZ SPORTS PROGRAM, REHABILITATION INSTITUTE OF CHICAGO

Meet Ken Johnson—World Class Athlete

Ken Johnson offers a strong rebuttal to the long-held belief that individuals with athetoid cerebral palsy have no place in competitive sports. Ken, a 29-year-old Chicago native, is the current national Boccia champion in his division. Boccia, an indoor version of the Italian game of lawn bowling, requires a high degree of skill to place the ball in the precise positions to eliminate competitors. Ken took up the sport just five years ago and has been ranked first in his class nationally for the last four. He has also completed internationally, representing the United States at the 1991 World Cup in Portugal, the 1992 Barcelona Paralympics, the 1993 World Cup in Belgium and the 1994 World Cup in England. He is a member of the U.S. team to the 1996 Paralympics in Atlanta. His training is supported by the Virginia Wirtz Sports Program at the Rehabilitation Institute of Chicago.

Ken is a recent graduate of Harold Washington Community College, where he studied computer programming.

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athletic, or otherwise—from teachers, peers or medical professionals. "I was always having to prove to others that I could do things on my own and that they did not have to treat me like a baby all the time," said one respondent. "Fortunately, my family treated me like an equal. They never let me be lazy or not want to accomplish things."

Some athletes mentioned the encouragement of siblings—"My older brother played college basketball," wrote one athlete. "I idolized him, and he drove me to try to be better than him."

Several respondents acknowledged that the support of their families often went well beyond psychological encouragement. One competitor noted that her family had to drive for an hour one way to bring her to the 50-meter pool where she practiced against swimmers without disabilities.

• **Training and injuries:** All survey respondents reported a strenuous training schedule of at least three to five days a week. These athletes, like many without disabilities, were firm believers in the benefits of cross-training—participating in a variety of conditioning and athletic activities in addition to practicing skills for a specific sport.

In response to the question about injuries, most respondents indicated that they had experienced at least minor problems, such as sore muscles and sprains. One participant reported needing knee surgery. Another reported being knocked down and injured slightly while running in a marathon with hundreds of other runners; she now wears a helmet when racing.

Some athletes with cerebral palsy reported developing chronic problems, such as tendonitis, after many years of heavy training and serious competition. Shoulder problems were a typical concern for wheelchair athletes.

Children participate in a game of team handball at the 1996 United States Cerebral Palsy Athletic Association Youth Nationals.

But according to Dr. Ken Richter, team physician for the United States Cerebral Palsy Athletic Association, athletes with cerebral palsy do not have a greater rate of injury than

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athletes without disabilities. Although they may suffer different types of injuries or chronic problems than their peers without disabilities, their injuries are no more serious. And as for the old concern about strength training increasing spasticity, more recent studies have shown that weight training can be beneficial to individuals with spasticity, as long as it is part of a properly designed conditioning program that also includes flexibility training.

Resources

United States Cerebral Palsy Athletic Association, 200 Harrison Ave., Newport, RI 02840; (401) 848-2460; (401) 848-5280 (fax); USCPAA@mail.bbs.net.com; http://www.USCPAA.org
USCPAA sponsors more than 80 regional events every year for individuals of all ages who have cerebral palsy or traumatic brain injuries, or who have survived strokes. Activities include archery, track, field, target shooting, power-lifting, bowling, cycling, swimming, boccia, cross country and ambulatory basketball. USCPAA-sponsored equestrian events are open to all disabilities. Membership is $10/year; first year free for children under 12. Financial aid, scholarships and stipends available.

Winners on Wheels, 2842 Business Park Ave., Fresno, CA 93727; (800) 969-8255; (209) 291-3386 (fax)
WOW offers 60 local programs in the U.S. for seven- to 12-year-olds who use wheelchairs. Activities include baseball, basketball, softball, soccer, tennis, hockey, table games, obstacle courses, arts & crafts, gardening, cooking and music. WOW also offers training in safety skills and wheelchair maintenance.

What about my child?

The athletes responding to the survey were unanimous in endorsing the benefits of athletic participation—of any kind, at any level. "I believe every child with a disability should be introduced to sports at an early age," wrote one, "because in our society, sports is a form of socialization. Participation in sports can give children the opportunity to be accepted by others."

Another athlete offered this straightforward advice to young people with cerebral palsy: "Decide what you want to do, and then go get it. Remember, ultimately, we set our own limitations." **EP**

Jan Little is a freelance writer, who lives in Chicago, Illinois. The author of IF IT WEREN'T FOR THE HONOR, I WOULD'VE RATHER WALKED *(Brookline Books, 1996), she often works with the Chicago mayor's office on accessibility-related concerns. Jan is a former Paralympic swimmer and archer who took home three gold medals from the 1964 Games held in Japan.*

Deborah Gaebler-Spira is an attending physician at the Rehabilitation Institute of Chicago and a member of the Sports Medicine Committee within the American Academy for Cerebral Palsy and Developmental Medicine. She lives in Chicago.

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Circle #50

Alternative Treatments

by Naomi Angoff Chedd

At some point, every parent of a child with a disability has felt that traditional treatment approaches have been ineffective or inadequate. It is probably safe to say that many, if not most parents, have thought about or even pursued alternative therapies and interventions. Are such treatments and traditional approaches at odds with each other, and do they need to be? Or can both be used simultaneously and harmoniously to achieve optimal results?

It depends on who you ask. Some medical practitioners feel they have an obligation to protect their patients from unsubstantiated claims, false promises or harmful, even lethal treatments. Others are more open to unconventional approaches, even if they would not personally prescribe them. According to Rick Rader, M.D., director of the Habilitation Center at the Orange Grove Center in Chattanooga, TN, many physicians *are* interested in alternative treatments. But he cautions, "Many patients run into trouble when they embrace unproven and unorthodox treatments and completely abandon traditional, scientifically tested interventions."

Susan Cable, an experienced physical therapist from Randolph, MA, agrees. "I integrate a variety of approaches into my treatments," she says. "I am NDT trained, but I also use myofascial release and craniosacral therapy. I think of them as adjunct, rather than as alternative therapies." (NDT, or neurodevelopmental therapy, is characterized by the consistent and correct handling and stimulation of children with movement disorders, especially cerebral palsy. It reinforces the development of normal movement patterns and typical skills and activities such as bathing, dressing, playing and toileting. Treatment procedures are integrated into everyday life, rather than practiced only once or twice a week in therapy sessions.) A number of Susan's patients get additional treatments such as acupuncture, biofeedback and nutritional therapy. "I often see changes when my patients use other treatments. I don't know if their progress is a result of one therapy or a combination of all of them. I just know that they are making progress."

What is an alternative treatment?

Alternative treatments, also referred to as nonstandard, unorthodox, unscientific or unproven, are approaches that:

- have not undergone rigorous scientific investigations or clinical trials;
- are not accepted by traditional medical practitioners;
- are not frequently used or have no consistent history of use; or
- do not provide an advantage over traditional treatments.

Although the benefits are questionable, every day many of us and our children use such treatments, contributing our hard-earned cash to a multibillion dollar industry. We take vitamins, pay for regular sessions with various body manipulators and try special diets and meditation regimens—despite evidence that these actions probably are not helpful for our particular conditions. We ingest and inhale herbs, listen to tapes of mating whales and voices of chanting monks, maybe because it provides a sense of control or calm and well-being. In addition to deriving comfort and pleasure and, in many cases, physiological benefits such as lowered blood pressure or body temperature, we hold out the hope that these practices may have some hidden, long-lasting healing powers. But mostly we do it because it makes us or our children feel better or because it certainly can't hurt—and might help.

Why?

The simple and obvious answer is that for many children with disabilities, traditional and standard treatment approaches don't seem to work. Or they don't yield the results that parents expect. Admitting their frustration with conventional approaches, the parents of a six-year-old with autism said, "Everybody tells us our son is making progress. But he makes no eye contact, has tantrums day and night, cannot speak one understandable word and is not toilet trained. We live with him, and we don't see any progress." Said a mother of a child with an undiagnosed physical disability and mental retardation: "I know my daughter will never be the same as other kids, not even close. But not one of the dozens of doctors or therapists we've consulted has a clue as to what she has or how to help her. So why shouldn't I try herbs, massage or howling at the moon, for that matter?"

Dr. Rader underscores that sentiment. "Conventional medicine is geared toward diagnosing and curing diseases. But most disabilities are not diseases, they are lifelong conditions. Developmental disabilities don't fall neatly into the traditional medical model. Moreover, since there is little or no chance of a cure for most disabilities, there is little incentive for doctors to go into the field." He points out that, although there are some outstanding practitioners in the field, "most medical schools simply don't prepare or encourage doctors to deal with children or adults with disabilities."

Understandably, many parents are starved for information, support, advice and especially for a treatment that will make a difference—some diet, medication or practice that will help their children function and feel better. Because so many traditional treatments fall far short of success, parents of

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children with disabilities, especially undiagnosed or degenerative conditions, are open to new approaches.

Two major categories

Alternative treatments can be divided into at least two major categories: those that are nutritionally based, and those that require some kind of neurophysiological training. The first includes such treatments as macrobiotic diets and other food regimens that include or completely omit certain substances such as sugar, preservatives, artificial additives, glutton or yeast. Megadoses of various vitamin/mineral/enzyme combinations are currently in vogue and are proported to treat conditions ranging from autism to hyperactivity to learning disabilities. Melatonin, motion sickness drugs and other medicines and herbs too numerous to list are being used in tremendous quantities for conditions such as sleep and mood disturbances, behavior difficulties and even in an attempt to improve intelligence test scores.

Similarly, some parents avoid foods packed with sugar and preservatives or give their children vitamins in addition to their prescribed daily doses of Ritalin or Valium. "You don't necessarily have to give up one to try the other," says one father of a child with ADHD (attention deficit hyperactivity disorder). "I'm not convinced that sugar *causes* hyperactivity, but my son goes berserk after a couple of cupcakes or a candy bar. I don't care what the research says. Sugar makes him crazy, so we avoid it." On the other hand, a mother of a child with dyslexia complains, "I'm sick of spending so much money on so-called miracle cures or subjecting my son to weird diets. Somebody is making a lot of money at our expense."

In the second category are such physical treatments as myofascial release (a manual therapy technique used to improve positioning and movement), craniosacral therapy (related to the skull and sacrum), applied kinesiology (the study of muscles and how they move), auditory training, conductive education, sensory integration and patterning. Various relaxation and visualization techniques, acupuncture, hypnotism, biofeedback, chiropractic treatment and osteopathy are still considered alternative in many circles, but they seem to be moving toward the mainstream and are widely used in many parts of the country.

Power in prayer?

Some parents and professionals suggest that spiritual pursuits and

continued on page 58

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practices should also be considered as treatment modalities and included in a comprehensive treatment plan. News stories, television and radio documentaries and new books on the subject appear regularly. In fact, a recent *TIME* magazine cover story ("Faith and Healing," June 24, 1996) presented evidence linking recovery after surgery and many other health benefits to faith and prayer—evidence that can no longer be dismissed. Many families report the use of spiritual practices as an addition to other methods of treatment.

Buyer beware

Although users and non-users of alternative therapies may have many differences of opinion, they do agree on some basics. Here are some guidelines for those thinking about nonstandard treatments:

- Consider the source. Who is trying to "sell" you the treatment? Is it a doctor or other medical professional? An organization that might benefit? A parent or patient who has had some success? What are this person's motives?
- Be cautious about overstated claims or treatments that can "cure" a wide variety of diseases, disabilities or ailments. Also, beware of any product that promises a quick fix.
- Avoid a treatment if the price seems outrageous and there is absolutely no evidence to back up its claims.
- Be sure to let your regular doctors and therapists know about any alternative therapies you are using or considering, especially if other drugs or herbal remedies are being consumed in addition to conventional medication. You may be unknowingly subjecting your child to harmful or conterproductive interactions.
- Educate yourself about any substance your child is consuming. A product labeled "natural" or "herbal" isn't necessarily good for you or better than a traditional medicine and may produce allergic reactions and side effects. **EP**

Naomi Angoff Chedd is a member of EXCEPTIONAL PARENT*'s editorial staff.*

In future issues, EXCEPTIONAL PARENT will take a more in-depth look at some new and alternative approaches to treating specific conditions. What topics or treatments would you like to see discussed? EXCEPTIONAL PARENT is interested in an ongoing dialogue with parents, children and professionals about their experiences with such treatments. We invite you to share your views with us.

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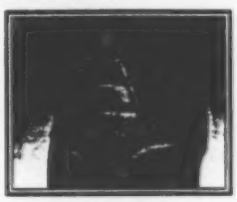

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Questions?

For conference information, call IBH at (415) 851-8411 For exhibit information, contact EXCEPTIONAL PARENT, PHONE: 800.EParent.
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Agenda

Thursday—October 17

7:30–9:30 PM Welcome Reception in Exhibit Hall:
Meet the Exhibitors, EXCEPTIONAL PARENT staff, and fellow attendees.

Friday—October 18

9:00–10:15 AM Welcome Address and Keynote Panel I:
Future of Family Healthcare for Those with Disabilities

10:30-11:30 AM Keynote II:
The Role of Sports and Play in the Development of Children with Special Needs

11:30 AM–1:00 PM Cash Lunch (on your own) in Exhibit Hall

1:00–2:45 PM Session I: Workshops & Roundtables

Estate Planning for Families	Ask the Doctor	Transporting Children with Disabilities	Fathers of Children with Special Needs	Inclusion: Pros & Cons	Transition Services

3:00–5:00 PM Session II: Roundtable Discussion

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

Saturday—October 19

8:30–10:00 AM Keynote Panel Discussion:
Who Should Be President of the United States?

10:15–12 NOON Session III: Workshops & Roundtables

People with Disabilities: Religion & Faith	What Happens When My Child Grows Up?	Bringing New Products to Market	Family Issues	Alternate Therapies	Children with Carnitine Deficienc

12 NOON–1:30 PM Cash Lunch (on your own) in Exhibit Hall

1:30–3:00 PM Session IV: Workshops & Roundtables

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

5:00–? PM 25th Anniversary Dinner & Disneyland
A fun evening of food, mingling, entertainment...and then rides and games in Disneyland. (Transportation not included)

Agenda

Sunday—October 20

8:30–10:15 AM Session V: Workshops & Roundtables

Making it Easier to Travel	Ask the Doctor	Role Models	Fathers of Children with Special Needs	Inclusion: Pros & Cons	Disability Issues & the Hispanic Community

10:30–12 NOON Special Closing Forum for Parents and Children

Optional Events

Thursday—October 17

2:00–4:00 PM Pre-Conference Workshops ($45 per person)
(Choice of one)

Funding & Where to Find It in Calif.	Seating & Position-ing Issues

Friday—October 18

7:00–9:00 PM Prominent Guest Panel Discussion: ($25 per person)
Well-known Personalities who either have Disabilities themselves or have Family Members with Disabilities or Special Health Care Needs

Registration

The following are the registration hours attendees can check into the conference

Thurs.—10/17	1:00–9:30 PM
Fri.—10/18	7:30 AM–7:30 PM
Sat.—10/19	7:30 AM–3:00 PM
Sun.—10/20	7:30–9:00 AM

Exhibit Hall

The following are the hours the Exhibit Hall will be open.

Thurs.—10/17	4:00–7:00 PM
(Conf. Attendees Only)	7:30–9:30 PM
Fri.—10/18	10:30 AM–5:00 PM
	7:00–9:00 PM
Sat.—10/19	9:00 AM–3:00 PM

Exhibit Hall Admission

Free to all conference attendees. Exhibit Hall Only Passes: $5 per day (children under 2: free). Purchase passes at the Exhibit Hall.

NOTE: All events and schedules are subject to change.

Invited Faculty

Honorable Edward M. Kennedy,
United States Senator
Ranking Member/Senate Committee on Disability Policy

Honorable Bill Frist,
United States Senator
Chair/Senate Committee on Disability Policy

James May, MA, MEd*
Project Director, National Fathers' Network

Rick Rader, MD*
Director, Institute for Developmental Medicine
Orange Grove Center

Ginny Thornburgh
Director of the Religion & Disability Program
National Organization on Disability

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❑ Fri. Evening Prominent Guest Panel ($25 x # of attendees) $____

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Health

Enteral Nutrition

PART ONE: When a child needs to get meals by tube

by Lee Barks

"Enteral" is an adjective defined as "having to do with the intestine." "Enteral nutrition" usually refers to liquid nutrition, delivered by tube directly into the stomach or small intestine.

Enteral nutrition, or "tube-feeding," is often used when a child cannot receive adequate nutrition orally—perhaps due to an obstruction of the esophagus (the tube that carries food from the throat to the stomach) or swallowing difficulties that increase the risk of choking and aspiration (breathing food or liquid into the lungs, which can result in pneumonia). In such cases, the only alternative to enteral nutrition is "total parenteral nutrition," or intravenous nourishment. This is not usually a good long-term solution because the intravenous solution, with its amino acids and vitamins, provides a rich medium in which bacteria can grow and dangerously infect the bloodstream. Enteral feeding is usually the best long-term solution unless the child has a problem with nutrient absorption, severe chronic diarrhea, severe inflammatory bowel disease or another condition that makes enteral feeding impractical.

To the parents of a child who has undergone a long period of illness and inadequate nutrition, enteral nutrition may seem like a blessing—and it is. Finding an answer to the question of how to provide good nutrition in difficult circumstances is a relief to everyone.

ABOUT THIS SERIES:
This is the first of several articles on enteral nutrition. Further articles will cover topics such as care of the stoma and tube, formulas and nutritional needs, positioning, oral motor difficulties and making the transition to oral eating.

Types of feeding tubes

Three types of feeding tubes are used to provide enteral nutrition:

• A *nasogastric tube* is threaded into one nostril, down the throat and esophagus, and into the stomach. This is a temporary tube—it blocks one nostril and is usually taped in place rather than anchored with stitches. Nasogastric tubes often hold open the muscle at the top of the stomach, allowing stomach contents to flow backwards into the esophagus, a condition known as gastroesophageal reflux (see sidebar below). This problem has been partially solved by new materials that have made it possible to use smaller nasogastric tubes.

• A *gastrostomy tube*, or "g-tube," goes into the stomach through a surgical opening in the abdominal wall. The g-tube is a flexible rubber catheter that remains in place at all times and is clamped between feedings to prevent leakage of stomach contents. A *gastrostomy button* is often inserted either initially or after a g-tube has been used for a while. The button, a small plastic device placed surgically

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Gastroesophageal Reflux

Ordinarily, when food gets into the stomach, a muscle at the junction of stomach and esophagus, the lower esophageal sphincter, acts as a one-way valve to prevent the food from coming back up. Newborn babies may "spit up" because this muscle is underdeveloped, but as they get older—usually by 12 months of age—and spend more time in an upright position, the muscle develops fully and the spitting up stops.

However, many children with cerebral palsy continue to have a problem with abnormal backflow of stomach contents into the esophagus. This is partly because spasticity can cause the abdominal or back muscles to contract, putting stomach contents under pressure. Often, the path of least resistance is upward, so these muscle contractions cause the stomach contents to flow backward into the esophagus.

The more liquid the diet, the less dense the material in the stomach. Because liquids flow back upward more easily than semi-solid stomach contents—such as chewed or puréed food—gastroesophageal reflux can be a particular problem for children who depend on enteral nutrition.

A child with gastroesophageal reflux disease (GERD) may not actually vomit but will experience the symptoms of severe heartburn. When stomach contents flow back into the esophagus, they bring along stomach acid and digestive enzymes, which can cause esophageal inflammation, or esophagitis. Over time, the esophagus can become ulcerated and bleed. Blood loss can lead to anemia, which results in lower disease resistance, energy and alertness. But the greatest risk of GERD is that the stomach contents will flow upward until they reach the level of the trachea, or windpipe, and are breathed into the lungs, resulting in aspiration pneumonia.

Some forms of reflux can be treated with a change of tube-feeding method, for example using the drip method (where the feeding is given slowly over a number of hours) as opposed to bolus (where the same amount would be given over a much shorter time period, at a much faster rate). Venting—opening the button or feeding tube to allow more air to escape from the stomach—may decrease reflux as well. A doctor may also prescribe medications, recommend changes in positioning or suggest the use of a different formula.

In some cases, doctors will opt to perform a fundoplication, a surgical procedure to narrow the opening between the lower end of the esophagus and the top part of the stomach. A child with a fundoplication may be fed orally or by tube; however, he or she may not be able to belch. This can be extremely uncomfortable; however, stronger gas may be vented through a g-tube or g-button.

Buying Some Time

Andrew, 19 months, knows how to find the coolest spot on a warm Florida day.

"By feeding your son orally, you are putting his life in grave danger," said the physician who had just done a complete diagnostic work-up on our 10-month-old son.

Andrew had uncontrolled seizures, severe hypotonia (low muscle tone), developmental delays and failure to thrive. The swallow study showed some reflux and a tiny bit of aspiration. My husband, Jim, and I thought it looked like no big deal. But the doctors were very concerned. They recommended that we start nasogastric tube feedings immediately, and then try to get his seizures under better control with medication. Nasogastric feedings were a short-term measure only, they explained. Soon Andrew would need to be evaluated for g-tube placement or a return to oral eating, but "you will find it increasingly difficult to feed him by mouth," warned the doctor. Tube feedings were ordered for 20 hours a day.

Andrew also began receiving intense oral motor therapy with the goal of strengthening his cheek, tongue and lip muscles, so he could eventually swallow more easily. Because Andrew had an asymmetrical chest, surgery to place a g-tube would be difficult. As long as Andrew's health was not in immediate danger, the gastroenterologist agreed to put off surgery as long as possible. He recommended thickening all formula and food to make it easier to swallow and continuing Andrew's therapy with the goal of complete oral eating.

Now 20 months old, Andrew has come a long way toward reaching that goal. He now receives half of daily caloric intake by mouth, and his daily tube feeds have been decreased from 20 hours to six. Before beginning the intensive oral motor therapy, he could drink about two ounces of formula in 40 minutes; today, he drinks twice that amount in half the time. He also eats pureed and chunky baby foods.

Although Andrew's muscles are getting stronger, his muscle tone can vary from week to week. We know that he could still end up with a g-tube. We accept that possibility, but we are grateful that the nasogastric tube allowed us to "buy some time" with which to give our son a chance to learn how to eat.

—Mary Kathryn Van Kleunen
Orlando, Florida

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in the stomach wall, allows the g-tube to be removed between feedings.

Children receiving enteral nutrition through a nasogastric tube or g-tube are given a specified amount of formula daily. Portions of the daily formula allotment may be delivered through the tube at regular "mealtimes"—each lasting 20 to 30 minutes. This is known as "bolus feeding." Or feedings may be given slowly, over a period of several hours, using the "drip method." Sometimes the formula is delivered at night, regulated by a feeding pump.

• A *jejunostomy tube*, or "j-tube," may be used to bypass the stomach when a child with a g-tube has problems with

A.J. Crooks (center) celebrates his fifth birthday with (from left) brother Matthew, 7, Dad, sister Rachel, 4, and Grandmom.

A Temporary Solution

Our son, A.J., was born at less than 24 weeks gestation, very small and very sick. By three months, he was strong enough to begin bottle-feeding, although it seemed to take forever just to get two ounces into him. He came home from the hospital a month later, but his feeding difficulties didn't improve; in fact, almost everything he ate came right back up. After two weeks of struggling to get him to eat and keep it down, we ended up back at the hospital.

Doctors discovered an ulcer on his esophagus, the result of gastroesophageal reflux. They labeled him "failure to thrive" and sent him home after prescribing frequent nasogastric tube feedings, a procedure that was torture for the whole family. A.J. cried through every feeding, and then spit up every drop we had given him. He continued to lose weight, and we were exhausted.

By the time he was eight months old—and only six pounds—it was time to place a gastrostomy tube. Because of A.J.'s continuing reflux problems, doctors also wanted to perform a fundoplication; but he had to weigh at least 10 pounds before that surgery could be done. That weight gain required four months of being hooked to pumps that dribbled his formula in at different rates. A few days before his first birthday, the fundoplication was performed.

The surgery resolved A.J.'s reflux problems, and he started to gain weight. Eventually, his g-tube was changed to a button appliance that allows us to remove the tube after each feeding.

A.J., now 5, continues to make progress. He's learning to use augmentative communication and is working with an oral motor specialist to master oral eating skills. I wish someone had told us we should continue to feed A.J. orally even after the g-tube was placed. This might have allowed him to follow the typical developmental progression from sucking, to chewing and swallowing. Unfortunately, because he was neither speaking nor eating orally, he developed jaw joint contractures, or facial tightness. Now we are trying to help him learn to use his mouth, cheeks and tongue to move food around his mouth properly; this will allow him to enjoy the wonderful tastes and textures of food for the first time. A.J.'s g-tube was a godsend when he needed it but, someday, we hope to bid it farewell.

—Diane Crooks
Lake Mary, Florida

vomiting and/or gastroesophageal reflux that cannot be resolved through medications or changes in feeding methods, formulas or positioning. A j-tube is inserted through a surgical opening in the abdominal wall and threaded into the upper small intestine—either directly or through the stomach.

Jejunostomy tube feedings are infused continuously because the small intestine is pressure sensitive. Food pushed into the small intestine with too much force or in too large an amount can trigger vomiting, cramps or diarrhea.

Preserving family mealtimes

An important issue for families has to do with finding ways to preserve regular mealtimes as an opportunity for family members to socialize, converse and eat together. I always suggest that the child receiving enteral nutrition join the rest of the family at regular mealtimes, even if he or she has special positioning needs. Talk and socialize as you have in the past, and infuse tube feeding at normal mealtimes whenever possible.

Family mealtimes can offer special learning experiences for children receiving enteral nutrition. Most importantly, they can begin to associate the satisfying feeling of fullness with the pleasant atmosphere of a family meal—including positive social interactions and the smells of good food. Although children receiving enteral nutrition may not experience the pleasant tastes and textures of oral eating, we can provide them with the associated and pleasant social experiences. This is especially important when an eventual transition to oral eating is planned. **EP**

Lee Barks, R.N., M.N., A.R.N.P., is the president and owner of Developmental Health, Inc., a firm that provides consulting services to rehabilitative and long-term care programs. She also works as a pediatric nurse practitioner at Pediatrics Plus, a private practice in Orlando, Florida, and as a consultant to the early intervention program at the Arnold Palmer Hospital for Children and Women, also in Orlando. She lives near Orlando with her husband and teenage son and daughter.

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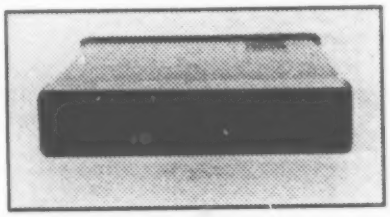

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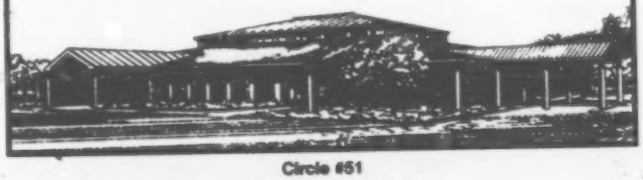

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WHAT'S HAPPENING

Pathways to Magic

Celebrating individuality and inclusion through the arts

At one of Chicago's six Pathways to Magic summer day camps, (from left) Vanessa Mendez, Brenda Iniguez and Ruth Liggett dance around Armando Salgado, who pops a wheelie in his chair.

The arts camps are Chicago's first inclusive, accessible summer day camp program—and among the first in the nation. The camps are a project of Chicago's Pathways Awareness Foundation, an organization dedicated to education for and about children with movement difficulties. The Chicago Community Trust, Chicago's community foundation, funds the camps, and the city of Chicago provides transportation and lunches.

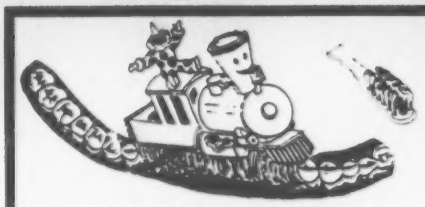
This summer, 120 campers are working with professional dancers, writers and drama coaches to prepare performances. One of every four campers uses a cane, wheelchair or walker. "The arts are very powerful for celebrating the individuality of people," says Maggie Daley, president of Pathways Awareness Foundation and wife of Chicago mayor Richard M. Daley. "Inclusive arts programs can provide excellence without exclusion."

For more information about inclusive programs, resources for children with movement difficulties or the Pathways to Magic day camps, call Pathways Awareness Foundation at (800) 955-2445.

On June 18, 1996, Stefano Cargnel, 18, a high school senior with spina bifida, carried the Olympic flame through Basking Ridge, New Jersey. Stefano, a wheelchair racer who is nationally ranked in track and field, was nominated by EXCEPTIONAL PARENT to be a torchbearer through Coca-Cola's "Share the Spirit: Who Would You Choose?" program.

"It was an amazing feeling," Stefano says. "Just having the torch in my hand brought a feeling of the history behind it. Once it was lit, all my nervousness faded away." And even though the weather didn't cooperate, Stefano reflects, "The crowd was wonderful. It seemed as though time stopped while they cheered. I'll never forget this."

Stefano has competed at the Junior National Championships for the past five years, and plays wheelchair basketball in a local adult league. He graduated this year from Carlstadt High School in Carlstadt, New Jersey. Stefano was featured as the May 1994 EXCEPTIONAL PARENT Role Model.



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Circle #65

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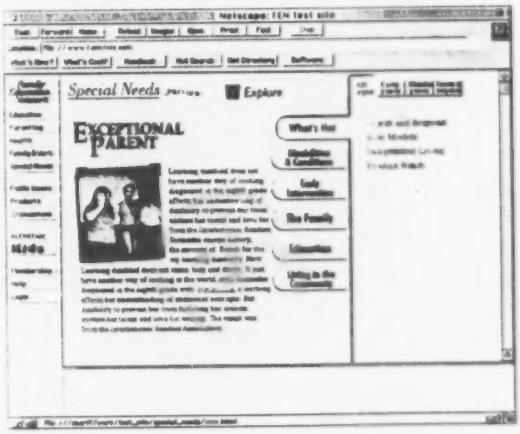
Circle #69

A New Family Education Network Is Born

by Ellen Goldberg

All of us at the Family Education Network (http://families.com) are gearing up for our launch date on September 12. We're very excited to announce that Richard Riley, U.S. Secretary of Education, will be kicking off our launch in Washington, D.C., and promoting September 12 as Technology Day of "America Goes Back to School" Week.

When you log on to the Family Education Network on or after September 12, you'll be greeted by lots of interesting features and surprises. Here's a little bit about what to expect.



Channel-surfing

The Family Education Network will consist of five main content areas called channels: Special Needs, Education, Parenting, Family & Work and Health. These will set the focus for all of the content on the service and will help establish Family Education Network as the trusted resource for families. The service will also offer "support channels," such as Public Policy/Advocacy, Discussions and Product Reviews, which will complement the main channels.

What's on tonight?

Special Needs—Based on an exclusive partnership between Family Education Network and EXCEPTIONAL PARENT. Find resources for specific disabilities and conditions, information to become a more informed advocate and financial and estate planning resources. Read about and discuss—with other parents and experts—new products and technology, family issues and alternative therapies.

Education—Resources and answers to questions about your children's schooling. Learn how to become more involved and a more effective homework helper. Learn how to use the Internet to create learning experiences at home.

Parenting—Insights and resources about raising kids today. Find out how safe your home really is, and how to determine your family's best child care option. Learn how to make quality time for your family.

Family & Work—Tips for balancing career(s) and family life. Find articles and resources on nutrition, tips on managing sibling rivalry, eldercare choices, family "stress busters" and creative ways to organize your family's free time.

Health—Scheduled for launch in the first quarter of 1997.

How do I use it?

We've devised four ways of accessing information on the Family Education Network:

- **Getting Answers:** A library of answers to everyday problems, complete with resources for in-depth information. In collaboration with EXCEPTIONAL PARENT, we're working with organizations such as The Arc, Learning Disabilities Association of America, National Organization for Rare Disorders, United Cerebral Palsy Association, and with members of EXCEPTIONAL PARENT's Advisory Board to provide us with questions and answers.
- **Ask the Expert:** Custom advice from professionals to help you solve your family's most pressing problems.
- **Explore:** Organized like a magazine's table of contents for easy browsing. Then, read the actual articles for in-depth information.
- **Search:** Type in a keyword to get related information from all the different channels.

The Special Needs channel will have its own unique area—Family Matching—comprised of two parts:

- **Search & Respond:** Based on *Search & Respond* in EXCEPTIONAL PARENT. For parents and professionals looking for other families with similar special needs. We've already had a phenomenal response in this area on our preview.
- **Family Matching:** In collaboration with already active matching programs throughout the world. Will include a confidential form for parents to fill out to find a matching family.

Future Special Needs channel ideas

In the Special Needs channel, we're planning to start a series of live conferences in the fall. Hosted by Stanley D. Klein, Ph.D., co-founder and editor-in-chief of EXCEPTIONAL PARENT and a clinical psychologist with over 40 years of experience working with children with special needs and their families, these conferences will enable you to discuss all kinds of concerns. Dr. Klein plans to invite other experts—parents *and* professionals—to join in sharing information about specific topics. Once conferences are up and running, we'll want to know what topics you're interested in. Please email your suggestions to elleng@families.com.

What do you say?

We're always eager to hear your comments and ideas. This service is for you, and we want to make sure it's as helpful as possible! If you have a need that's not being met or ideas that you'd like us to try out, don't be shy—send your messages to elleng@families.com. **EP**

Ellen Goldberg is a producer at the Family Education Network in Boston, Massachusetts.

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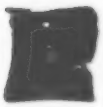

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Circle #23

"Caregiver Disorder"

Recognizing an unacknowledged illness

by Suzanne Geffen Mintz

There are between 18 and 25 million family caregivers in the United States—nobody knows the exact number. We provide two-thirds of all the home care in this country, thereby playing a very active and necessary role in our health care delivery system. In the process of caring for our family members, however, we often develop a pattern of symptoms that puts our own health at risk.

In 1994, the National Family Caregivers Association conducted a member survey. The caregiver profile that emerged was frightening. To begin with, 49 percent of respondents reported experiencing prolonged depression—not surprising in light of the other findings. For example, 69 percent said that the emotion they most associated with caregiving was frustration (only two percent said it was peace or joy), and 41 percent said that the change in family dynamics and the isolation that accompany caregiving were debilitating. Forty-seven percent felt burdened by a lack of leisure time, and 65 percent reported getting no consistent help from other family members.

Other studies have shown similar results and pointed out that caregivers tend to neglect their own health, letting existing conditions exacerbate. Approximately 20 percent of caregivers develop new medical problems as a result.

Unseen and invisible

Family caregivers are ill-served by our current healthcare system. Our "symptoms" are not categorized; we are not the subject of ongoing research or articles in medical journals. I suspect this isn't intentional, but, rather, a by-product of our invisibility.

That's because family caregiving is largely unseen. Most caregiving occurs in the home, behind closed doors. Nobody watches as you struggle to get your child dressed. Nobody witnesses the physical strain of lifting a heavy teenager or the effort of getting up three or four times a night—every night—to assist a child with a developmental disability.

Family caregiving is about chronic, long-term care—not short-term, cure-oriented care, which is the focus of traditional health care. The professionals who treat our loved ones are focused on fixing structural abnormalities of the body. We are focused on trying to create a better quality of life for ourselves and our families.

Our experiences are outside the norm, and if caregiving is about any one thing, it is about the loss of normalcy. We caregivers and our care recipients spend an inordinate amount of time figuring out how to do those basic activities—things like eating, dressing and toileting—that the "healthy," able-bodied world takes for granted. Health care providers rarely see this aspect of our lives.

A family affair

Health care professionals see us only as the sad-faced people who come to visit our loved ones in the hospital. We are the ones who drive their "patients" to physical therapy and administer medications at home. We are family. We are not considered to be patients, too.

But the truth is that chronic illness and disability are truly a family affair. When someone we love is diagnosed with cerebral palsy, Down syndrome, leukemia or the like, we caregivers develop our own condition. "Caregiver disorder" needs to be recognized as a very real syndrome—one that is treatable with education, proper psychosocial and medical attention, and an appropriate level of help and support from others. But it can't be treated until caregivers, the health care community, policymakers and the general public recognize its existence. Caregiving needs to lose its cloak of invisibility.

Telling our stories

I am tired of being invisible. I am tired of not being recognized as an important player in our health care system. But we will not get the attention we need and deserve until we begin to tell our stories. We need to let people know that we invisible caregivers provide more $190 billion dollars worth of free services every year—services that cannot readily be replaced. We need to let people know that neglecting family caregivers will put even more strain on an already over-burdened health care system.

I have suffered twice from clinical depression. I don't ever want to be that ill again. I don't want to put my own life and, therefore, the life of my husband, at such risk again. I want my personal physician to write "caregiver" on my chart, and I want my husband's physician to verbally examine me, review my progress and watch out for symptoms that might spell trouble.

I want all of these things to happen because I believe it is vitally important that our health care system recognizes the existence of family caregivers and gives us the respect, honor and very real attention we deserve. If it does that, ultimately it will be providing better care, not only to us, but to our care recipients as well. **EP**

Suzanne Geffen Mintz has been a family caregiver for more than 20 years. She is the president and a co-founder of the National Family Caregivers Association (NFCA), a not-for-profit membership organization dedicated to improving the quality of life for family caregivers. For more information, contact NFCA, 9621 E. Bexhill Dr., Kensington, MD 20895-3104; (800) 896-3650; (301) 942-2302, fax; email: CAREGIVING@aol.com.

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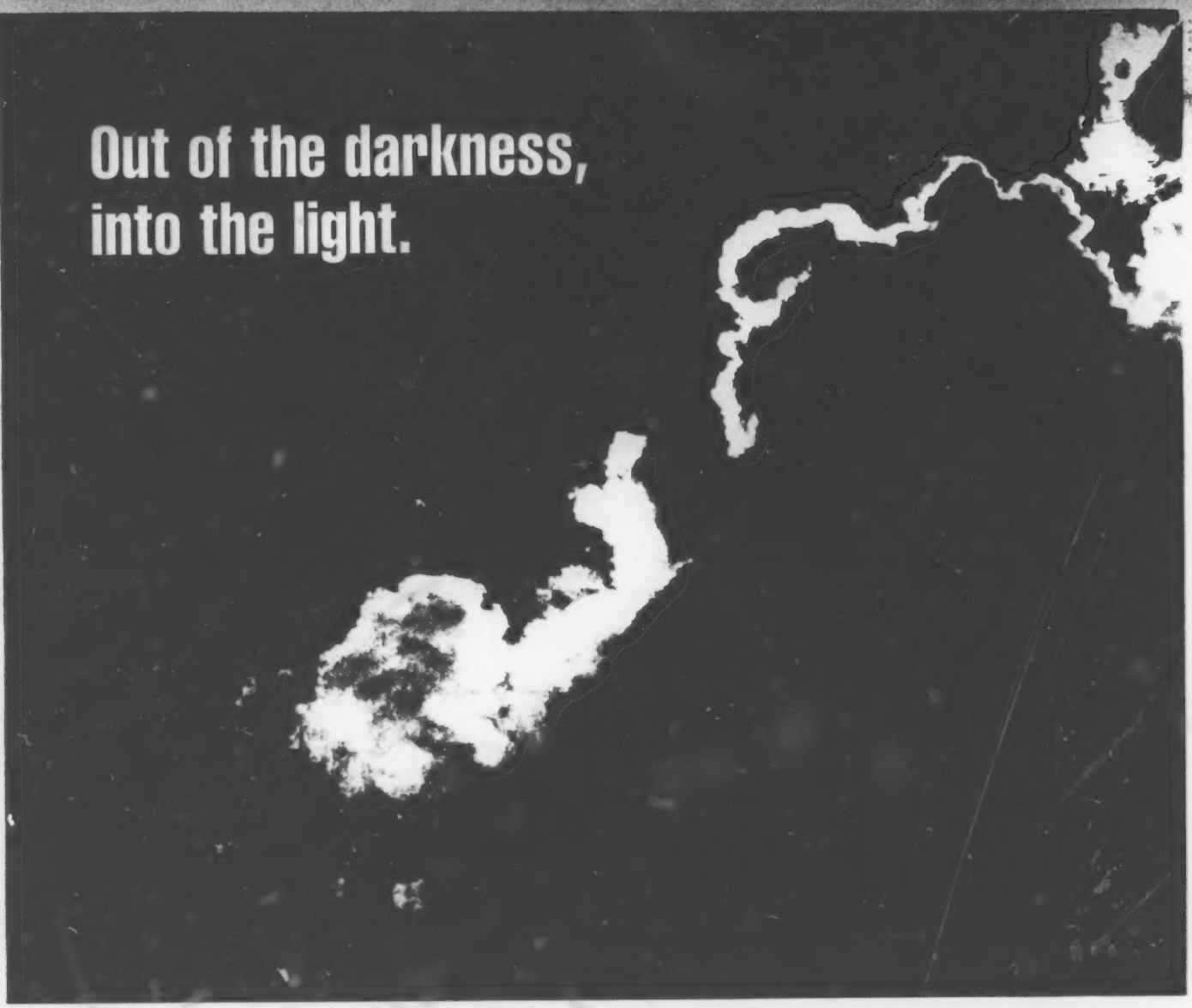

The National Organization for Rare Disorders (NORD) and *Exceptional Parent Magazine* will be *"Stepping Out in Dallas"* to bring you a conference you will not want to miss.

FOR WHOM: People and families of those affected by rare disorders and Professionals (social workers, nurses, educators)

WHEN: September 27 through 29, 1996

WHERE: Marriott Quorum
14901 Dallas Parkway
Dallas, Texas 75240
(214) 661-2800

FEES: Registration Fees **NORD Member $85.00**
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Each Additional Family Member $70.00

The Marriott Quorum is offering a special room rate of $89.00 per night single/double occupancy for NORD conference attendees.

Dallas is the place to be when NORD and *Exceptional Parent Magazine* go "Stepping Out" together and join forces in arranging a truly 'exceptional' Patient/Family Conference. You won't want to miss the chance to meet with other individuals and families coping with rare disorders. Workshops and speakers will address issues and concerns that are important to those in the rare disease community. • Living with a Rare Disorder • How to Access Resources • Making the Most of Networking • Patients' Rights and Responsibilities • Support Systems • and much more! Interactive discussions are also planned with experts in metabolic diseases, assistive technology, genetic research, insurance reimbursement and the psychology of living with chronic disorders. There will be many opportunities to meet others coping with rare disorders!

If you are interested in receiving additional information on the conference and registration, kindly fill out the coupon below and mail to the address indicated before August 31, 1996. You may also contact NORD at 1-800-999-6673 and speak with either Jean Campbell (ext. 210) or Joseph Gatto (ext. 211). Space at the conference will be limited, so call now to guarantee a reservation.

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Telephone: _____ **NORD Member:** ☐ **Yes** ☐ **No**

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Place in an envelope and mail to:
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Requests for conference information should be received no later than August 31, 1996.

Circle #28

Health

MANAGED CARE

Standards and Criteria for Children with Special Health Care Needs

In 1995, the National Coalition for Family Leadership, a group of national family leaders—all parents of children with special health care needs—gathered for their annual working retreat. Based on the discussions, the group developed its own quality standards and criteria for managed care, particularly with regard to families of children with disabilities or chronic illnesses.

The coalition's report explains what families of children with special health care needs should look for in a managed care plan. Parents can use the report to: help employers choose an employee health plan; guide Medicaid contracts with health maintenance organizations; educate hospitals or pediatricians when they become part of a managed care system; or assist state Part H programs as they consider managed care contracting for early intervention services.

The following is a summary of the report, which contains the National Coalition for Family Leadership's vision for managed care:

• **Families are the core of any health system:** Managed care systems will acknowledge and support the expertise that families bring to their caregiving, decision-making and care-coordinating roles. Managed care systems will accept and value the diverse traditions and languages that families bring to health care settings, and will provide families with the information and resources they require. Services will be delivered in response to needs identified by families and providers. Families will thereby have the supports necessary to make informed decisions.

• **Family-professional partnership:** Managed care systems will recognize that outcomes for children with special health care needs improve when families and professionals make decisions jointly. Each party will respect the expertise, experiences, training and resources that the other brings to the care of the child. (See definition of *family-centered care* in sidebar on this page.)

• **Access:** Managed care systems will provide unconditional and equitable access to quality primary, preventive, habilitative and specialty health care services and equipment at a reasonable cost to the family. The child's health will be the primary goal, overriding all other considerations and decisions. If gatekeepers are used, they will be well-trained, monitored by families and professionals, and make their decisions in partnership with the family and other health providers. ("Gatekeepers" is a term that refers to primary care providers who must pre-approve all other medical care including referrals, diagnostic studies, hospitalizations and therapies.)

• **Flexibility:** Managed care systems will provide effective, flexible health care and services to children with special health care needs. Medical decisions and referrals will be based on the unique circumstances of the family and the condition of the child.

• **Comprehensive, coordinated, community-based care:** Managed care systems will assure a coordinated system of comprehensive services to children with special health care needs and their families through direct service provision within the plan, and collaboration with public and private community services outside the plan. The services will be delivered as close to the child's home as possible, and will include appropriate outreach to underserved families, prevention, education, screening, diagnosis, primary and specialty care, mental health services, wellness management, hospitalization, emergency care, medications, supplies, equipment, habilitation and rehabilitation.

Applying the principles

• **Access:** *In a family-centered managed care system, children with special health care needs receive primary, acute and specialty care and services in a prompt, timely and barrier-free manner.* Access includes adequate and realistic enrollment information, foreign language translators as needed, screening for disabilities or chronic health concerns, a comprehensive health plan for each child, prior permission for referrals to specialists, care coordination and services close to home, with flexible hours.

• **Benefits:** *In a family-centered managed care plan, a full range of necessary health care services are provided for children with special health care needs and their families.* Adequate benefits include a primary care provider who will oversee the child's health care and make referrals to other providers, access to all needed services, programs that promote prevention and wellness, access to the latest technology and behavioral health services, in-home care and equipment, coverage from time of application and referrals to alternate resources and interventions outside the network that can include non-traditional or unique treatments.

• **Capacity:** *In a family-centered managed care system operating to*

Working Definitions

Managed care is a way of financing and delivering health care for a set fee, using a network of specific providers and services. A managed care organization can be either a for-profit or not-for-profit corporation that refers its patients to health providers, clinics and hospitals within its own network. A managed care system coordinates services within its network and monitors the amount, cost, quality and patterns of care provided. A managed care system also has the responsibility to make referrals outside its network for those services it cannot provide.

Family-centered care is a philosophy and approach to service delivery. Information-sharing and collaboration between families and providers are the cornerstones of family-centered care. Family-centered practitioners recognize and support the vital role that all families play in ensuring the health and well-being of their children.

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its capacity, qualified personnel and adequately developed policies and systems are in place to serve children with special health care needs and their families. Capacity means that the managed care system has well-trained staff who live in the community served, quality assurance standards, strong financial resources within the network, administrative capabilities for running a health network, information about emergency care, a resource library, patient access to one's own or one's child's records and compliance with the Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act.

• **Decision-making:** *In a family-centered managed care system, families are part of the decision-making process.* Families understand the benefits of the managed care plan and work with other team members to make treatment, equipment and therapy decisions. Families are involved in the development of programs and policies.

• **Evaluation and data:** *In a family-centered managed care system, quality assurance standards and patient satisfaction and monitoring mechanisms are developed in partnership with families and are utilized to improve the policies and services provided.* This means that families help develop and update criteria for standards, and that the network shares information about care and outcomes with families, makes consumer satisfaction and feedback a priority, measures the effectiveness and patterns of referrals, has processes in place for resolving patient disputes with care providers and the network, makes patient demographics available to consumers, and publicly reports on costs of care, administrative overhead costs and information provided annually to shareholders.

• **Financing:** *In a family-centered managed care system, families and providers work together to ensure that every child receives the best possible care for the money.* Providers' salaries are based on their skills and expertise with children with special health care needs; costs to families are reasonable; equipment and other resources can be loaned to families; and families participate on review boards that monitor costs, reimbursements and expenses. **EP**

For more information, contact: Bev Crider, Michigan Department of Health (800/359-3722); Josie Thomas, Institute for Family Centered Care (301/652-0281); or Polly Arango, Family Voices (505/867-2368). For a copy of the ABCs OF MANAGED CARE: STANDARDS AND CRITERIA FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS, *send $1 and a self-addressed, stamped, legal-size envelope to The National Coalition for Family Leadership, 2990 Syckelmoore, Trenton MI 48183.*

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Circle #47

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Health

Self-Care for Caregivers

by Brenda Crumpton Sumrall

"What you need is a break! Make some time for yourself."
"I couldn't do all that you do! Aren't you just exhausted?"

Parents of children with disabilities and special heath care needs often hear comments and suggestions of this sort. Although indicating that the speaker at least partially recognizes the significant stress family caregivers experience, these comments may strike parents as naive, insensitive or just too simplistic. But such statements do contain a bit of truth—parents must care for themselves as well as their child.

When a child is diagnosed with a disability or chronic illness, parents may experience a multitude of stresses—grief, financial hardship, negative sibling reactions, the need to learn about and deal with complex social systems and technology, changes in relationships and disruptions in usual activities. Still, most families adapt to their changed circumstances and, somehow, manage to accomplish what needs to be done. Most even come to recognize that parenting a child with special needs can provide wonderful rewards. But it's no wonder they often feel overwhelmed.

It's easy to convince ourselves that we must put our children's needs first, but experienced parents often find that they can best provide care for their child when they pay special attention to taking care of themselves. Replenishing your own energy and well-being allows you to have more to give to your child; failing to replenish it eventually leads to physical and/or mental exhaustion.

Parents who have coped successfully with the demands of parenting children with disabilities or special health care needs have suggested a variety of self-care techniques:

• **Adopt a healthier lifestyle:** Try to set a regular schedule for meals, exercise and rest. You may not be able to stick to your routine every day, but having a schedule makes it harder to skip healthy activities and provides needed structure for your child's day as well.

Kicking unhealthy habits, such as overeating or smoking, is an admirable goal, but remember that even moderate reductions will yield health benefits.

Research has linked regular exercise to a reduction in depression and an increase in energy. Walking or jogging is inexpensive; you may even be able to bring your child along in a stroller or wheelchair if necessary.

Some parents have an understandable tendency to stay up late or work through mealtimes to accomplish necessary tasks, but eating regular meals and getting enough rest will result in improved work performance and efficiency.

• **Seek out support:** It's important to build a support bank of positive people you can tap into when you're feeling alone. Local support groups and national disability-specific organizations can provide not only emotional support, but also practical advice and assistance. You may also be able to establish a connection with a parent whose situation is similar. Your health care provider or medical social worker may be able to help with this.

• **Take control in the face of uncertainty:** All parents worry about the "what if's." Parents of a child with special needs may have additional concerns about life's unpredictability, but having a contingency plan can reduce worry.

Prepare a list of helpers and their phone numbers, alternatives for transporting your child, back-up sources for medical equipment and numbers of emergency, safety, and medical personnel.

A call or visit to your local fire station and EMT/ambulance company may help you feel more confident about their ability to respond to your child in an emergency. Such visits also give you an opportunity to share information about your child's needs. If appropriate, have your child's physician send letters to utility companies documenting your child's need for priority services in the event of outages.

Even if you have never needed daycare, respite or home health care, it can be a good idea to explore these services as possibilities for unusual circumstances, such as your own unexpected illness or injury. It's much easier to establish a relationship and choose a service provider *before* a crisis occurs.

Preparing a will, establishing a trust fund and making other arrangements for the care of your child in the event of your death can also increase your peace of mind.

• **Set realistic goals and celebrate achievements:** Break big goals down into smaller ones and reward yourself at each step.

• **Develop a healthy sense of humor:** People facing incredibly stressful circumstances have often found that humor can take away some of the sting of misfortune. The ability to laugh—and laugh at oneself—is a sign of mental health and growth. Expose yourself regularly to humorous books, cartoons and people.

• **Don't neglect your spiritual needs:** Your church or synagogue can be a safe haven and a place for recharging your batteries. Some congregations may offer special programs for your child while offering you respite as well. **EP**

This is one of a series of articles prepared in collaboration with the National Perinatal Association (NPA, 3500 E. Fletcher Ave. Ste. 209, Tampa, Florida 33613-4712). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time of birth) health issues from preconception through infancy. Brenda Crumpton Sumrall, ACSW, LCSW, BCD, is Director of Social Work and an instructor in pediatrics for University Hospitals and Clinics, University of Mississippi Medical Center in Jackson, Mississippi. She is also a member of the NPA Board of Directors.

Gaucher Disease*

by David Hirsch, M.D.

Q Our 18-year-old daughter was recently diagnosed with Gaucher disease. She has been healthy all her life, but at a recent physical examination, her doctor determined she has an enlarged spleen; further evaluation led to the diagnosis. Apparently, the gene for this disease runs in our family. My cousin's child had what I think was Gaucher disease when she was very young, but she was always sick and died before the age of four.

My cousin told me that a medication is available to treat this illness. What do you think about it? My cousin has also been wondering why her child was not offered this treatment.

A Gaucher disease is an inherited disorder, the most common of the so-called "storage" disorders. (Tay-Sachs disease is probably the best-known of these.) Gaucher disease is caused by a deficiency of the enzyme glucocerebrosidase, which is responsible for breaking down and digesting glucocerebroside, a by-product of the normal recycling of red blood cells.

Because individuals with Gaucher disease cannot break down glucocerebroside, it remains stored in some cells of the body. Organs containing these "Gaucher cells" may become enlarged and stop functioning properly. Gaucher disease most often affects the spleen, liver and bone marrow. However, it can also affect the lymphatic system, lungs, skin, eyes, kidney, heart and, in rare cases, the nervous system.

Although most common among Jews of Eastern European (Ashkenazi) descent, Gaucher disease occurs in individuals of all ethnic groups. It is extremely variable in its signs and symptoms, ranging from severely affected infants to asymptomatic adults.

Gaucher disease is usually categorized as one of three types. Type 1, sometimes called the "adult" or "chronic" form, is the most common. This form of the disease is most commonly diagnosed in the late teens, but may occur at any age. It often involves the spleen, liver and bone marrow, but spares the central nervous system.

Type 2, formerly called "infantile" Gaucher disease, is a very rare, rapidly progressive form of the disease, characterized by severe and significant involvement of the nervous system as well as the organs affected by Type 1 Gaucher disease. The onset is usually in the first few months of life. Children with this illness generally do not live past two years of age.

Type 3, formerly called "juvenile" Gaucher disease, is almost as rare as Type 2. Characterized by a slowly progressive neurologic disease, symptoms of Type 3 Gaucher disease appear in early childhood. Other than the nervous system involvement, Type 3 symptoms resemble Type 1. Individuals with Type 3 Gaucher disease who reach adolescence may survive into the third or fourth decade of life.

Historically, treatment for all forms of Gaucher disease has been supportive. At one point, bone marrow transplantation was found to be an effective therapy for affected individuals in which the central nervous system was not yet involved. Unfortunately, this form of treatment turned out to carry unacceptably high risks of graft-versus-host disease.

More recently, enzyme infusion therapy (giving the needed enzyme intravenously on a periodic basis) has been used as a treatment for Type 1 and, to a lesser extent, Type 3 Gaucher disease. This therapy uses either imiglucerase or alglucerase, both of which are forms of the enzyme glucocerebrosidase. The treatment appears especially promising for Type 1 Gaucher disease; however, further studies are needed to determine the optimal dose and duration of the enzyme infusion therapy, as well as the best time to begin treatment. In other words, is it better to start before or after symptoms first appear? In the future, Gaucher disease and other enzyme-deficiency diseases may be treated with gene therapy.

Given your daughter's age, and your description of her symptoms, it appears that she has the Type 1 form of Gaucher disease. You and she should discuss the possibility of enzyme replacement therapy with her physician. Your cousin's child probably had Type 1 Gaucher disease also, but with an unusually early age of onset and more severe symptoms. Even if enzyme replacement therapy might have helped her, since that treatment has come into use only in the last four or five years, it might not have been available when she first became ill.

For more information, you may wish to contact the National Gaucher Foundation, 11140 Rockville Pike, Ste. 350, Bethesda, MD 20852; (800) 925-8885. **EP**

Our thanks to Dr. Robin Berman of the National Gaucher Foundation, who reviewed this month's column.

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT'S *Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 209 Harvard Street, Suite 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).*

Supplemental Security Income

by Frank L. Brunetti

Q My 10-year-old daughter has cerebral palsy. My husband and I have been told that she may be eligible for monthly income from the Supplemental Security Income Program (SSI). My husband and I both have good jobs. Why would our daughter be eligible for government money?

A Administered by the Social Security Administration (SSA), SSI provides supplemental monthly income of up to $470 (this amount is supplemented by some states) to people in one of two categories: 1) individuals who have a disability (as defined by SSA) and don't have a lot of income or assets, and 2) individuals who are older than age 65. Based on the severity of your daughter's cerebral palsy, SSA will determine if your daughter meets its definition of "disability." SSA considers children younger than 18 to have a disability if they are unable to "function" as other children of the same age.

In determining financial eligibility, SSA will look at your daughter's income and assets. SSA considers two types of income—earned income, which includes job wages and payment for work done in a sheltered workshop or work center; and unearned income, which includes support and maintenance provided in kind. "In kind" means that all food, clothing and shelter you provide for your daughter will be considered as part of her unearned income. SSA will also consider your daughter's assets. To meet SSI eligibility, your daughter cannot have assets worth more than $2,000.

Since your daughter is under the age of 18, probably does not work, and most likely does not have more than $2,000 in assets, she could be eligible for SSI benefits even though, as you indicate, you and your husband both have "good jobs."

If, however, your daughter does have cash resources in excess of $2,000, there are some steps you can take. You can spend her excess cash or assets on home modifications or equipment related to her disability, establish a burial fund for her or establish a special needs trust (see "Trusts for Children with Disabilities," February 1996). In making its determination of financial eligibility, SSA does not consider any of the above as assets.

Another option is to use your daughter's resources to buy a "life estate" in your home. A life estate would give your daughter partial ownership of the house and the right to live there until she dies. This can be a good option because SSA also bases eligibility decisions on an applicant's living arrangements. For example, if your daughter meets SSA financial eligibility requirements and lives in her own home—meaning that she pays rent, pays her share of household expenses *or* has a life estate in the residence—she will be entitled to full SSI benefits.

If your daughter continues to live in your home after she reaches the age of 18, but does not pay a proportionate share of the household expenses, she will be entitled only to a maximum of two-thirds of the basic SSI benefit rate. To avoid this situation, your daughter could pay you market-value rent and her share of living expenses. Or you could treat her room and board as a loan if you can prove to SSA that the loan is legitimate by obtaining an appraisal for the value of the rent and drawing up a repayment agreement, which should be based on a realistic anticipation of repayment.

If, once she reaches age 18, your daughter will be living in public or private residential housing and Medicaid will be paying for more than half of her care, her SSI benefits will be very limited. But if she lives in a publicly operated community residence for 16 or fewer people, or in a public residential program that mainly provides education or job training, she will probably still be eligible for full SSI benefits.

To apply for SSI, your daughter must file an application (available at any SSA office) along with a statement of income and assets. Since your daughter is a minor, you can complete the application for her.

Technically, there is no waiting period for SSI; once an application is approved, benefits are paid retroactively to the application date. However, the approval process can take several months.

If your daughter's application for benefits is denied, you can file an appeal. See "SSI Rejections and Appeals" (*Health Insurance Troubleshooter*, February 1995). **EP**

For more information...
Contact your local Social Security office or the Social Security Administration, 6401 Security Blvd., Baltimore, MD 21235; (800) 772-1213, voice; (800) 325-0778, TTY; (410) 965-0695, fax. Helpful publications, such as *Supplemental Security Income* (#05-11000) and *Benefits for Children with Disabilities* (#05-10026), are also available at SSA's World Wide Web site (http://www.ssa.gov).

In this column, attorney Frank L. Brunetti answers questions about any aspect of estate planning involving a child with a disability. Mr. Brunetti, a professor of law and taxation at Fairleigh Dickinson University in Teaneck, New Jersey, has written extensively on the topic of estate planning for families who have children with disabilities.

Send questions to: Estate Planning, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146-5005; (617) 730-8742 (fax).

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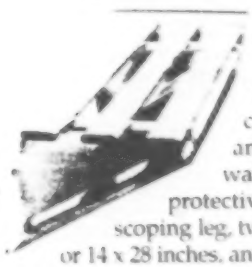

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Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card (page 58) to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Coverage for Speech Therapy

by Richard Epstein

Q We live in California and have a five-year-old son who has been diagnosed with pervasive developmental disorder (PDD). He has been receiving speech therapy since he was two and a half years old. At age three, he had tubes placed in his ears, which improved his speech and language skills dramatically. For the past year, we've been battling our private insurance company over payment for his speech therapy.

Over the years, we've been subject to delays in payment because of periodic reviews by our insurance company. In April 1995, the company conducted another review. Seven months later, they agreed to cover our son's speech therapy from the previous April, when the review was initiated, to September, but took the position that the therapy was "not medically necessary." They told us we would have to submit daily therapy notes for all claims after September.

Since then, although we have submitted therapy notes and doctors' letters, the claims have not been paid. The insurance company has indicated that they will not cover the therapy because our son has shown only minimal progress. Our policy has an arbitration clause. Should we proceed, or is there some agency we should contact?

A I think it's essential to begin with an understanding of the way health insurance policies generally deal with services such as speech therapy. Originally, many policies provided coverage only for hospitalization. Later, they began to cover doctors' office visits, x-rays, outpatient medical tests and specific medical treatments for a wide variety of conditions. Eventually, coverage was also extended to psychological therapy, physical therapy, speech therapy and other non-medical services.

As coverage expanded, companies developed different rules. For example, payment of speech therapy claims often requires that patients show continuing progress. Usually, companies require detailed, written documentation of such progress.

Unfortunately, some insurance companies seem to rely on generalized, computer-generated statements when communicating with consumers. As a result, it's often difficult to understand what they are trying to say. It's also important to understand that insurance companies use technical terms in a specialized way. "Not medically necessary" can mean two different things: either that the insurance company requires additional documentation—such as doctors' letters or therapists' reports—to determine whether or not the treatment is "medically necessary" or that the insurance policy does not cover the treatment.

Thus, I think your first step should be to talk to a supervisor at your insurance company and try to determine which of these meanings the company has in mind. If by "not medically necessary" the company means that further documentation is required, you can ask your child's doctor and speech therapist to provide additional reports.

Judging from your letter, however, your insurer seems to be using "not medically necessary" to mean that your son's speech therapy is not covered under the policy. If that is the case, you need to consider the next step.

Arbitration is one possibility. In arbitration, an arbitrator listens to both sides in a dispute, and then makes a decision. Arbitration carries some risk because, in many cases, the arbitrator's decision is binding.

Before agreeing to arbitration, it's essential to obtain legal advice. Protection and Advocacy, Inc., a California agency with extensive experience in health insurance issues, should be able to help you. Call them at (800) 776-5746 (California only; to find a similar office in another state, contact the National Association of Protection and Advocacy Systems, 202/408-9514, voice; 202/408-9521, TTY; 202/408-9520, fax).

You might also explore the possibility of obtaining speech therapy through the public school system. If it can be demonstrated that speech therapy is directly related to your son's educational needs, and if it is listed in his IEP (individualized education plan), the school system will pay for it. Protection and Advocacy, Inc., may be able to offer advice on this issue as well.

You can also contact the American Speech-Language-Hearing Association (800/638-8255) and ask for "Do Your Health Benefits Cover Audiology and Speech Language Pathology Services?" This free brochure offers tips on understanding insurance policies and getting coverage for speech therapy.

In addition, I think it is important that you write to your state legislators. The state legislature has the authority to regulate health insurance (except for policies issued by self-funded plans). It is essential that legislators hear the experiences of consumers. **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146; (617) 730-8742 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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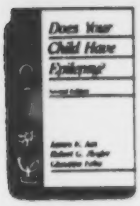

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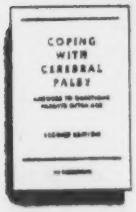

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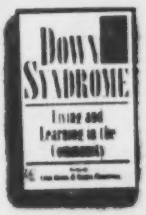

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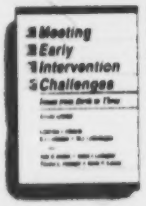

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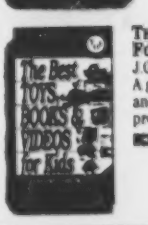

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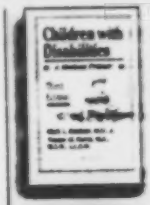

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My Brother, Artie

by Louis Perwien

Artie (left), [illegible] Louis, 13, relax [illegible]

My brother, Artie, is one year younger than me. In many cases, this would mean we would be the best of friends. Artie would be someone I could have fun with, someone with whom I could share my deepest thoughts and feelings. But this is not the case. Artie has mental retardation and acts like he is four or five.

He hasn't yet mastered the art of using a knife or staying dry overnight. He is always singing Barney tunes in the car as he picks his nose. (Incidentally, he has the best voice in the family).

Don't get me wrong. I love my brother, but sometimes I wonder what it would be like if a different sperm had met a different egg. Would we be similar or different? The best of friends or the worst of enemies?

In many ways, Artie is the sweetest guy you could ever hope to meet. Recently, I was in the hospital. When I got home, Artie immediately hugged and kissed me. Neither of my other siblings did that.

But there are times when I wouldn't mind having a different brother. Like when I have friends over and he walks by my room wearing nothing but his diaper. Or when we are in a restaurant and he starts screeching for no apparent reason. I can feel people staring, and I know they're thinking, "What's wrong with that kid?" I know they just don't understand, but I still get upset. I'm not sure who I am most upset at—Artie for screaming, others for not understanding, or me for being unable to accept the whole situation.

When I was younger, I was ashamed of Artie. I never had friends over—I was afraid they would see him. When I drew pictures of my family, Artie was always missing. At one point, nobody even knew I had a brother.

But as we have grown, Artie has become my favorite sibling. You may think that is strange, but then, you haven't met my two younger siblings. They annoy me at least as much as Artie, but when they do something to bother me, they do it to spite me. When Artie annoys me, it's just Artie being Artie.

I love Artie more than you can believe. And even though he doesn't say it, I know the feeling is mutual. I can see it in his eyes when we play a game and in his smile when I sing with him. I can hear it in his laughter when I talk to him. To paraphrase Barney, "I love him; he loves me; we're a happy family."

A doting brother from an early age, two-year-old Louis pushes a sleeping Artie in his stroller with a little guidance from their father, Mark.

Louis, 12, locks siblings Pamela, 5, and Ben, 7, in a loving stranglehold. Rounding out the picture is their dad, Mark, and Artie, 11.

Louis Perwien, 15, lives in Montclair, New Jersey with his parents, Mark Perwien and Laurie Goodman, and his siblings, Artie, 13, Ben, 9, and Pamela, 7. This fall, Louis will enter his sophomore year at Montclair High School. He enjoys writing and bicycling.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *Exceptional Parent,* 209 Harvard Street, Suite 303, Brookline, MA 02146-5005.

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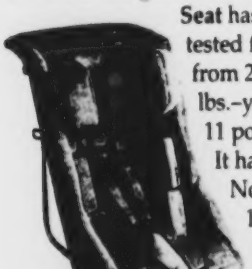

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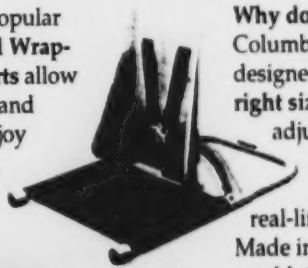

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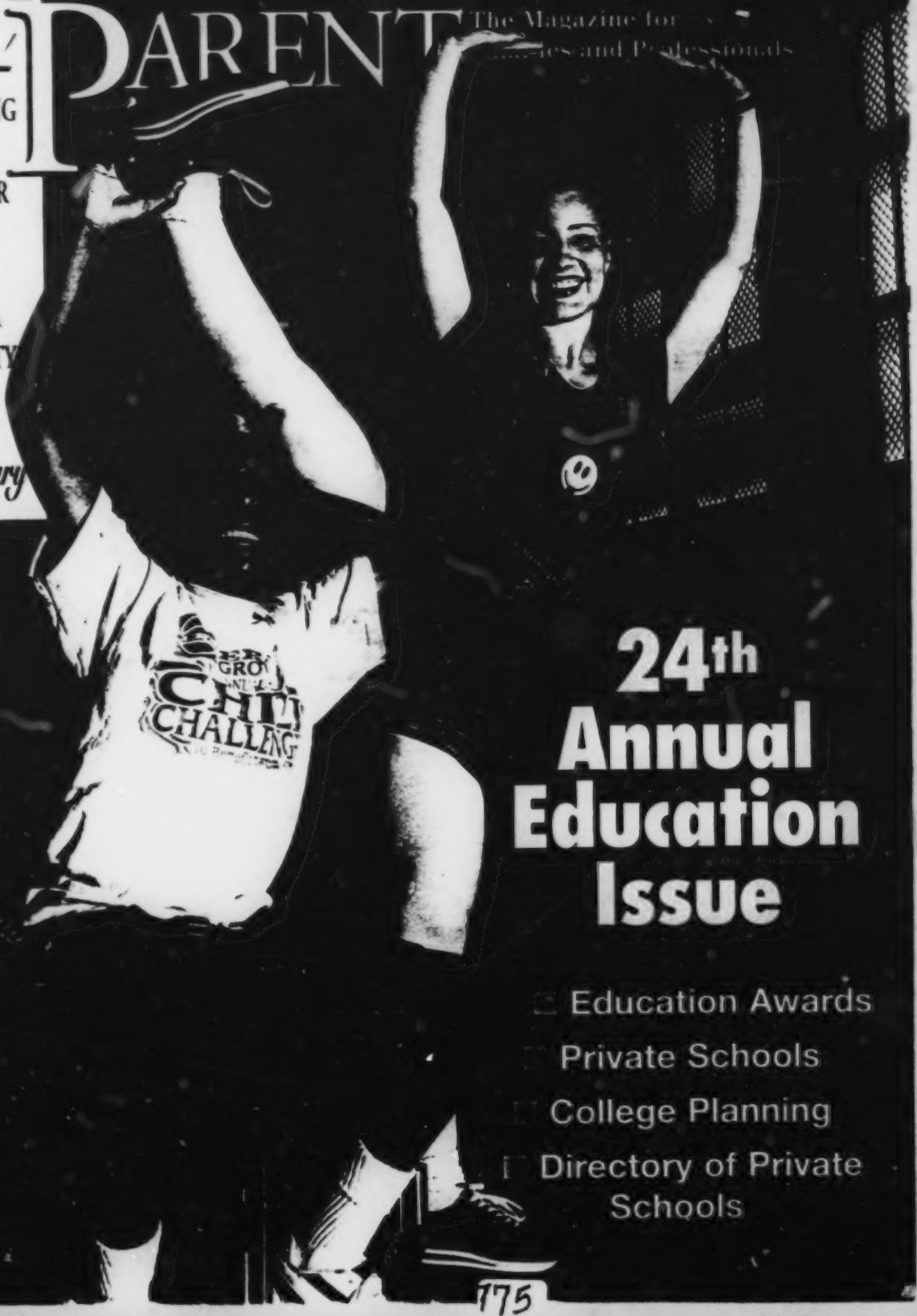

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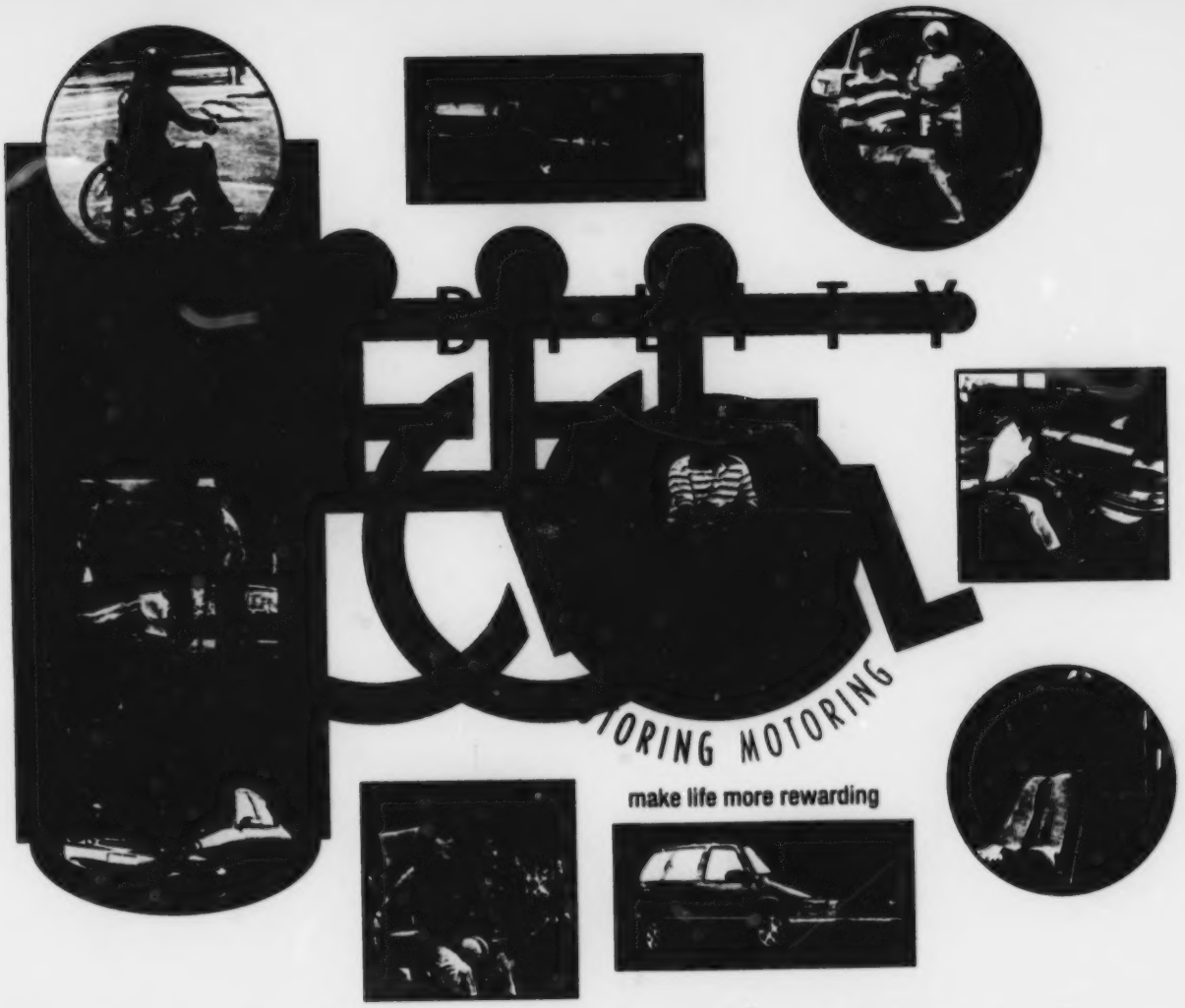

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SEPTEMBER 1998 VOL. 28, ISSUE 9

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Cover: Camper Grant Gillespie (left), 12, and instructor Wendy Taylor strike a pose at Chicago's Magic City Camp, a free day camp that gives kids the opportunity to explore multimedia arts, particularly photography and dance. The camp, one of six Pathways to Magic summer camps, is open to any child.

This photo is one of a series taken during a special photo shoot. First, the campers warmed up by stretching—each participating at a comfortable level. After warm-up, camp instructors videotaped each child running or moving and then striking a pose at a designated spot. The poses were freeze-framed so the children could examine them and decide which moves worked well together. Then, the kids broke into smaller groups and, using their knowledge of dance and photography, as well as the photographer's suggestions, composed camera shots.

For information on the Pathways to Magic summer camps, call Pathways Awareness Foundation at (800) 955-2445. Photo: Paul Rizzo.

Special thanks to Kathy Schaeffer and Kirsten Dirks of Kathy Schaeffer & Associates for their help in arranging this photo.

BPA

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EDITOR'S DESK

Honoring Excellence, Respecting Choices

Our 24th annual education issue illustrates the results of many people's continuing efforts to improve educational opportunities for all children with disabilities. In "Dispelling the Myths of Special Education," Judy Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education, describes some specific improvements and clearly refutes recent media attacks. "School Daze," Abby Albrecht's account of college life, also illustrates improving opportunities for young persons with disabilities.

STANLEY D. KLEIN, PH.D.

With the collaboration of the National Association of State Directors of Special Education, this issue honors public school programs illustrating quality inclusive education. We also honor a publicly funded charter school for children who are deaf and a program that combines private special education with public education.

EXCEPTIONAL PARENT has sometimes been criticized for accepting private-education and residential-program advertisements. We support inclusion and also support educational alternatives. We support each child's right to receive an education that respects his or her unique needs. Most of all, we support the expertise of parents as they endeavor to make wise choices in the best interests of their children and their families.

Changes

Thanks to the unrelenting efforts of three caring senators—Nancy L. Kassebaum (R, Kansas), Edward M. Kennedy (D, Massachusetts), and Pete V. Domenici (R, New Mexico)—and many parents and people with disabilities, federal law regarding health insurance has changed in two ways. First, individuals and families will no longer be blocked from getting health insurance because of so-called "pre-existing conditions." Second, health insurance will now be "portable," meaning individuals can change jobs without fear that they will be turned down for insurance through a new employer. Unfortunately, Senator Domenici's efforts to improve coverage for mental illness failed, but we know he and his colleagues will continue to be dedicated to making further needed changes in the law. We urge readers to thank the legislators who supported these new regulations.

In "A Letter From the March of Dimes," this organization responds to the article ("So, Why Was Your Baby Born Early?" February 1996) and letters critical of their public education efforts linking prematurity and birth defects with maternal behavior. Once again, the actions of individual parents made a difference—just as they have in education and health care.

On September 1, EXCEPTIONAL PARENT's publishing office moved from Hackensack to nearby Oradell, New Jersey. At the same time, the editorial office was combined with the publishing office. I will continue to work from Brookline, Massachusetts, and visit the new editorial team regularly. J. Carlisle Spivey is our new managing editor. With this change, several staff members have moved on to new positions; we wish them well and thank them for their fine efforts.

Countdown to Forum '96

Readers from across the country have already signed on for the celebration, educational program and the exhibit show at Forum '96, October 17–20 in Anaheim, California. There is still time to join us for the entire weekend or for just one day. Please complete the registration form on page 86. See you in Anaheim!

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EXCEPTIONAL PARENT

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For subscription and advertising information, see page 86

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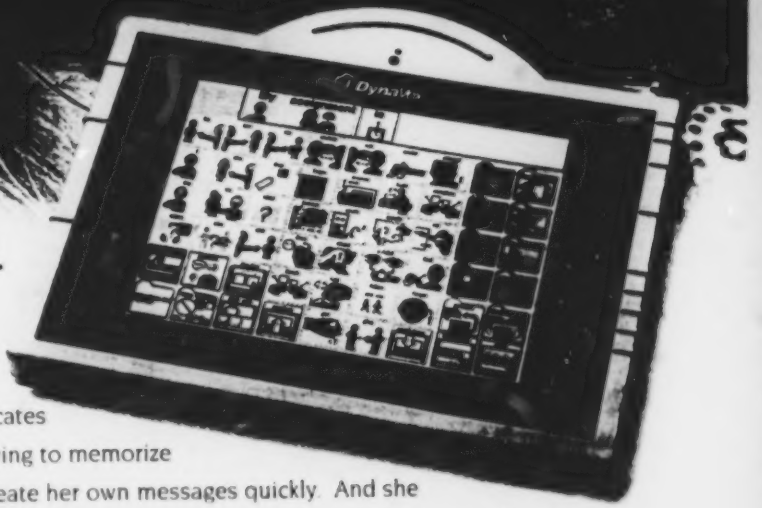
Find out more about Forum '96!

Get detailed information on attending Exceptional Parent Live:
- Go to the Family Education Network at http://www.familyeducation.com;
- Click on the "Special Needs" section, located toward the bottom of the screen;
- Scroll down to the end of the screen and click on "Come to Forum '96!"

We hope to see you there in October!

Breakthroughs



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Circle #70

LETTERS

Still an Exceptional Parent

I want to thank Esther Epp-Tiessen for the article "No Longer an Exceptional Parent" (July 1996). I, too, lost a child to brain cancer. In fact, as a way of cursing the darkness, I did not renew my subscription to EXCEPTIONAL PARENT for awhile after Heidi's death in 1991. But, in my work as an occupational therapist, I came back to the magazine because I have never found a finer journal of its kind.

I admire Ms. Epp-Tiessen's honesty about what she liked about being an exceptional parent—I, too, had these feelings, but was afraid to share them. Knowing that someone else felt the same way helps me feel that my own feelings are more normal and acceptable.

But as I look forward to my other daughter's wedding, I have come to a different understanding. Although Rebecca has reached adulthood, I am still her parent. In the same way, I now realize that I will always be an exceptional parent, even though Heidi died. These experiences remain with you even after your children leave—whether they leave with a spouse, move to another country or pass away.

The part of me that was an exceptional parent makes me a unique occupational therapist because I have a unique bond with other parents. I've been there. I can share my experiences both as a parent and professional. In fact, I am now working with a little girl who has brain cancer. Finally, I can share all that I have learned with another family.

R.B., Maryland

Sleepless in California

Yesterday, I finished up my household tasks around 10:40 p.m. At that point, I thought, "I'll just read the new issue of EXCEPTIONAL PARENT for about 15 minutes before going to sleep. I read one story, and then another, and then another—the next thing I knew, more than an hour had passed. I need my sleep! Do you have to print such interesting articles?

Actually, I'm writing to say thank you for publishing a great magazine with such valuable information and interesting stories. My four-year-old son, Malcolm, has Williams syndrome with significant developmental delays, but I have never felt isolated. This is due to some wonderful professionals who do not view Malcolm's life as a tragedy. Rather, they see him as a special person with valuable gifts to offer.

We've also received a lot of valuable information and

continued on page 6

Correction

August's *Estate Planning* column ("Supplemental Security Income") indicated that when determining SSI eligibility for a child under the age of 18 who lives at home with his or her parents, the Social Security Administration (SSA) considers only the child's income and assets. The article indicated that to be eligible for SSI, a child cannot have more than $2,000 in assets.

This information was incorrect. According to SSA, if a child is under 18 and lives at home, the parents' income and assets are also considered. For a family of four, the maximum income eligible for SSI is approximately $25,000; the maximum value of assets is $3,000. We apologize for the error.

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PRODUCT NEWS

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Circle #77

LETTERS

continued from page 4

support from the Williams Syndrome Association through their national and regional conventions, social gatherings and quarterly newsletter. And, of course, EXCEPTIONAL PARENT has been a great source of information and support.

I especially enjoyed reading the very moving articles on the two little boys who died ("No Longer an Exceptional Parent" and "Remembering Daniel," July 1996). The death of a child is one of a parent's greatest fears, and these articles confronted the subject with great sincerity. Much of the media has a fascination with tragedy, combined with a tendency to put a glossy finish on everything in an attempt to fit emotions into neat, little packages. This combination of sensationalism and superficiality is disturbing. EXCEPTIONAL PARENT, on the other hand, treats difficult subjects in a way that is both satisfying to read and reflective of people's actual experiences.

In the June issue, I enjoyed reading about the number of people helped by *Search & Respond*. What a wonderful networking device! I also enjoyed Ed Martin's article ("The Golden Age of Special Education"). I'm grateful to the people who worked so hard to get laws passed, so public schools cannot say, "Sorry, we won't accept your child because he has a disability." It's so important that we don't lose the progress that has been made.

I'm sure you must receive many letters, but I wanted to add my voice and express my appreciation. Your work has a very positive impact on many lives!

T.R., California

continued on page 8

Tell us about...

...the early intervention services you received when your child was younger.

Which services were helpful?
Which were not?

Write to: *Readers Talk, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201)634-6598 (fax). A sampling of reader responses to this question will appear in a future issue.*

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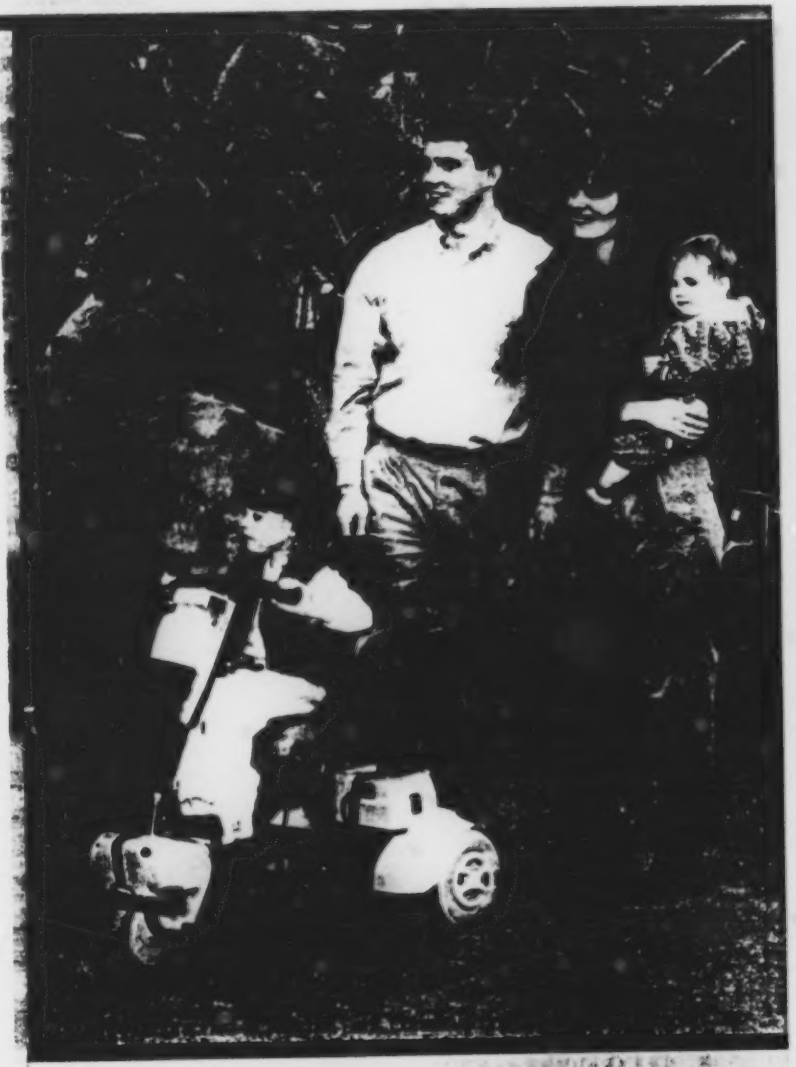

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MARTHA LLOYD COMMUNITY SERVICES

Circle #94

continued from page 6

Another Juggler

Your July issue arrived at the perfect time for me to read "Readers Talk About: Juggling Family and Career." I have a four-year-old son with cerebral palsy as well as a four-month-old infant. Returning to work part-time was an agonizing decision. Fortunately, my employer gave me the opportunity to work three days per week. Unfortunately, I will be taking a demotion and a sizable pay cut. Nevertheless, the balance between work and family will become much easier. It's nice to know that there are others out there who can do it, too!

L.V., Wisconsin

Give Us Some Laughs!

I love receiving your magazine each month and read it almost cover-to-cover as soon as it arrives. My husband and I are the parents of two sons. Our older son, Tom, 17, has atypical pervasive developmental disorder or Asperger syndrome.

Sometimes it's very difficult dealing with the outside world when your child has an invisible disability like high-functioning autism. When a child appears "normal" but acts strangely, others tend to blame the child's parents. We've even seen this attitude from relatives and teachers.

However, my purpose in writing is not to complain, but to compliment. We deal with our son's condition and many other issues with the help of the support group some friends and I started a few years ago. EXCEPTIONAL PARENT has always emphasized the importance of support from other parents, and how right you are! In fact, I plan to pass around the "Diagnosis of the Month" article from your July 1996 issue at our next meeting.

Sometimes we feel like saying, "We've had our fill of medical and educational information—give us a few laughs!" The Mothers from Hell are absolutely terrific, and I'm so glad you printed that short, but hilarious piece. Please give us more!

M.C., Connecticut

Behavioral Disorders and Mental Illnesses

I have been reading your magazine for many years now. It is my favorite because I can identify with the feelings expressed by the parents who write. However, my concerns are somewhat different.

My 21-year-old son has mild cerebral palsy. In addition, he has sensory motor problems and attention deficit disorder (ADD) and has recently been diagnosed with bipolar disorder, also known as manic-depression.

My 16-year-old son has Tourette syndrome (TS). Known primarily for the tics that must be present for its diagnosis, TS is frequently associated with other disorders that can affect one's life very seriously—ADD, obsessive compulsive disorder, depression, anxiety and sleeping problems. My son has all of those.

I had hoped that diagnoses, medication, therapy and special education would make my sons' lives easier and happier. Lately, I've been wondering if easy, happy lives are possible for my boys. It's very painful to watch them struggle.

Please include more information about behavioral disorders, mental illnesses and the children who have them. All the intelligence and talent in the world means nothing if it's strangled by anxieties and behavior problems. And suicide can be every bit as fatal as infections or heart disease. These children also get hospitalized, use special education and, sometimes, need residential placement.

There are many of us who could use the feeling of connection that your magazine offers. I know you'd do a good job of presenting information related to these disorders. Sometimes it feels very lonely out here.

B.B., California

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax). Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication but enables us to contact letter writers directly if necessary.

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SEARCH

Trichorhinophalangeal Syndrome

My 15-year-old daughter, Gillian, has been diagnosed with Trichorhinophalangeal syndrome, type 1, a condition characterized by hair-and-bone abnormalities. I am interested in contacting other families dealing with this syndrome.

J.R., Massachusetts

EDITOR'S NOTE: Both types of trichorhinophalangeal syndrome are forms of ectodermal dysplasia, a group of skin-and-bone disorders. The National Foundation for Ectodermal Dysplasias (P.O. Box 114, Mascoutah, IL 62258-0114; 618/566-2020; 618/566-4718, fax; nfed@aol.com, e-mail) can provide information on your daughter's disorder and can help you and her get in touch with other parents and children who are dealing with this condition.

Dandy-Walker Syndrome

My 13-month-old son is an alert and bright child who has been diagnosed with Dandy-Walker syndrome, a disorder characterized by a malformation of the fourth ventricle of the brain (one of the chambers in which cerebrospinal fluid is made and circulated). This malformation results in congenital hydrocephalus.

He goes to physical therapy and infant stimulation classes, but we do not know what to expect in the future. I would like to hear from other parents who have experience with this disability.

N.S., San Jose, Costa Rica

EDITOR'S NOTE: The Dandy-Walker Syndrome Network (5030 142nd Path W., Apple Valley, MN 55124; 612/423-4008) can provide information about Dandy-Walker syndrome and can put you in touch with other parents of children with this condition.

Pachygyria

My two-year-old son, Cale, has been diagnosed with pachygyria, a brain disorder. This is a rare condition for which we can find very little information. He has moderate delays; he can't walk or talk yet. I am hoping to find other parents who have children diagnosed with this condition.

K.A., Kansas

EDITOR'S NOTE: The Lissencephaly Network (714 Autumn Ridge Ln., Fort Wayne, IN 46804; 219/432-4310, voice/fax) can provide more information on pachygyria.

14q- With Translocation Trisomy 8

My seven-year-old daughter was diagnosed at birth with 14qt, a chromosomal abnormality. I recently learned that her correct diagnosis is a 14q- with a trisomy 8 that translocated to 14. I have been able to find only limited information on each of these abnormalities individually and no information on these abnormalities occurring together. I would like to hear from parents who have a child with either of these chromosomal disorders.

J.C., California

Only One Lung

My eight-year-old son, Matthew, lost one part of his left lung when he was eight days old; he lost the other part at 13 days. He had two problems with his left lung—congenital lobar emphysema and adenoid cysts.

His doctors have different opinions about his breathing problems, but none of them have ever dealt with a child who has only one lung. I wonder if there are non-drug options for helping him breathe, maybe some physical activities?

A.T., New York

Feeding Disorder?

Our six-month-old daughter, Jessica, has an undiagnosed feeding disorder. She has low muscle tone, no facial expression and a minimal gag reflex. She has great difficulty swallowing

continued on page 12

EXCEPTIONAL PARENT
Parenting Your Child or Young Adult With a Disability
The Magazine for Families and Professionals
Since 1971

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
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and aspirates (breathes food into her lungs) when she does swallow. After extensive speech, occupational and physical therapy and many months with a nasogastric tube, we hesitantly allowed placement of a gastrostomy tube. We would like to hear from parents who have a similar child.

F.P. & J.P., New York

Frequent Vomiting

Our four-year-old son has spina bifida; Arnold-Chiari malformation, type II (a malformation of the brainstem) and gastroesophageal reflux (a condition in which stomach contents flow backwards into the esophagus). He has average intelligence and an especially outgoing personality.

Medications control the reflux well with his meals. However, whenever he gets anxious or nervous, he vomits, even several hours after eating. His pediatrician says he will outgrow this, but it has gotten more frequent in the last few months for no apparent reason, and seems very clearly related to his emotions. We are not even sure if the problem has more to do with the reflux or the Arnold-Chiari malformation. We would like to hear from anyone whose child has had a similar problem.

D.W., South Carolina

Chromosome 13q-

Our 17-month-old daughter, Rachel, has a chromosome anomaly called 13q-, a partial deletion of the long arm of the 13th chromosome. She has cerebral palsy, cortical visual impairment and a moderate to severe hearing loss. She is fed by g-tube. Doctors believe that her cortical visual impairment and cerebral palsy are due to a lack of oxygen and/or brain hemorrhage at birth. We are unsure as to the cause of her hearing loss.

We would like to correspond with other parents of children with 13q- and/or parents of children who have any of Rachel's other disabilities, especially cortical visual impairment.

M.B. & K.B., Tennessee

Walker-Warburg Syndrome

Our son was born in February 1995 with severe hydrocephalus. A shunt was placed 24 hours after his birth. After a week of testing, doctors diagnosed him with Walker-Warburg syndrome, a severe brain, eye and muscle disorder. They gave us a rather bleak outlook on his prospects. He currently receives his food and seizure medications via a gastrostomy tube, placed when he was one month old. We would like to hear from other parents of children with this rare syndrome.

M.E., Massachusetts

Leigh Disease and Dystonia

We adopted our daughter, Lauren, when she was seven weeks old. Except for bilateral nystagmus (involuntary, rapid eye movements), diagnosed at three months, she seemed perfectly healthy until the age of 15 months, when she started falling while sitting and crawling. She never walked independently.

Based on an MRI done at seven months, a CT scan done at 15 months, and many lab studies, she has been diagnosed with subacute necrotizing encephalomyopathy or Leigh disease. Skin and muscle biopsies did not reveal any enzyme deficiency.

Lauren is non-ambulatory, non-verbal, fed by g-tube and completely physically dependent. Cognitively, she is on age level She currently takes riboflavin, biotin thiarine, coenzyme Q and Carnitor.

Lauren has developed significant movement disorders as a result of the damage done to her brain and basal ganglia. She has choreoathetoid movements (slow, writhing movements with a jerky component) and dystonia (severe muscle spasms), for which she takes Arkine, Baclofen and Klonopin. The dystonia continues to be an especially difficult problem.

I am interested in networking with other families who have children with Leigh disease and/or dystonia. I am especially interested in talking with anyone who has a child with secondary dystonia (dystonia resulting from another, primary condition).

L.S., Massachusetts

EDITOR'S NOTE: The Dystonia Medical Research Foundation (DMRF) can provide information on dystonia and can help you contact parents of other children who have dystonia as a secondary diagnosis. Contact DMRF, One E. Wacker Dr., Ste. 2230, Chicago, IL 60601-1905; (312) 755-0198; (312) 803-0138, fax. (Canadian readers can contact DMRF at 116-230 Heath St. W., Toronto, ON M5P 1N8; 800/361-8061; 416/487-8326, fax). Both American and Canadian branches of DMRF can be reached by Internet e-mail (dsytfdtn@aol.com) or on the World Wide Web (http://www.iii.net/biz/dystonia.html).

The National Leigh's Disease Foundation (608 E. Waldron St., P.O. Box 2222, Corinth, MS 38834; 800/819-2551; 601/286-2551, fax) can provide information about Leigh disease and help you network with other parents of children with this condition.

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812; (800) 999-NORD; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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RESPOND

Down Syndrome and Ketogenic Diet

P.S. (May 1996) is the mother of six-year-old Kyle, who has Down syndrome and an uncontrolled seizure disorder. P.S. had tried the ketogenic diet once before, but had to discontinue it—before it had a chance to work—because Kyle aspirated the whipping cream used for fat intake and ended up hospitalized with pneumonia. P.S. would like to try the diet again, possibly using oil instead of whipping cream, but first wanted to hear other parents' experiences using the diet with a child who cannot be reasoned with and who does not eat well.

My advice is to give the diet another try! My 14-year-old foster daughter, Elizabeth, has had seizures since 11 months of age. Elizabeth, who has multiple disabilities, has used many anticonvulsants without achieving anything close to seizure control. For the last year, she has been on the ketogenic diet.

Elizabeth does not chew, so all her food must be mashed. She refused to drink milk before starting the diet and, not surprisingly, refused to drink cream once we began. I tried all sorts of flavorings and dilutions—all to no avail.

Clearly, I needed to come up with more creative solutions, and I did. For one thing, I have developed recipes using Knox unflavored gelatin to make a creamy gelatin of cream, canola oil, sweetener and flavorings—she loves it. I also mash together cream cheese and butter, add flavorings, and serve it with beef or chicken and a vegetable. I cook the cream into scrambled eggs and make cheese quiches. I also make cheesecakes. If Kyle likes the taste of cream, he might be able to drink it without aspirating (breathing liquid into his lungs) if it is diluted with water or soda. You could also use the cream to make ice cream or hot chocolate.

N.N., Pennsylvania

EDITOR'S NOTE: For more information on the ketogenic diet, readers can investigate these resources:

- *THE EPILEPSY DIET TREATMENT: AN INTRODUCTION TO THE KETOGENIC DIET (paperback, 1994, 180 pp.): Demos Publications, 386 Park Ave. S., Ste. 201, New York, NY 10016; (800) 532-8663; $21.95.*
- *AN INTRODUCTION TO THE KETOGENIC DIET: A TREATMENT FOR PEDIATRIC EPILEPSY (video, 45 min.): The Charlie Foundation, 1223 Wilshire Blvd., Box 815, Santa Monica, CA 90403; free.*
- *THE JOHNS HOPKINS KETOGENIC DIET FACT SHEET (4 pp.): The Epilepsy Foundation of America, 4351*

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Circle #67

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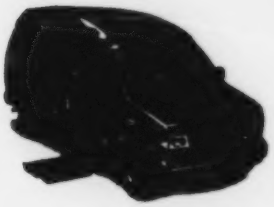

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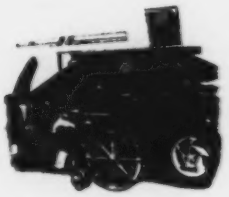

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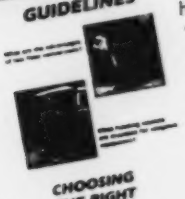

To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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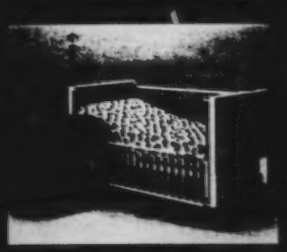

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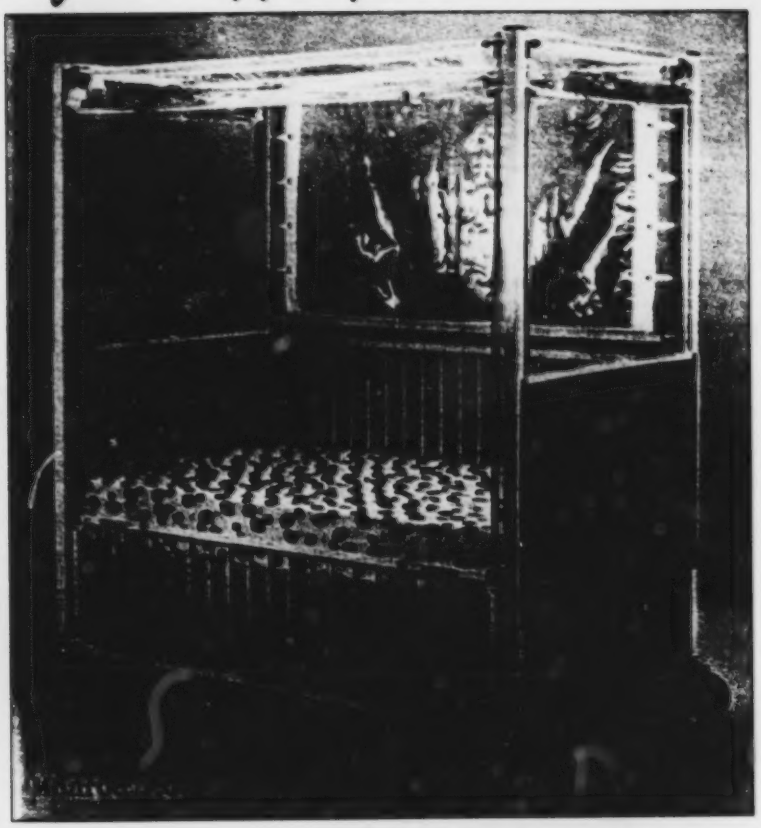

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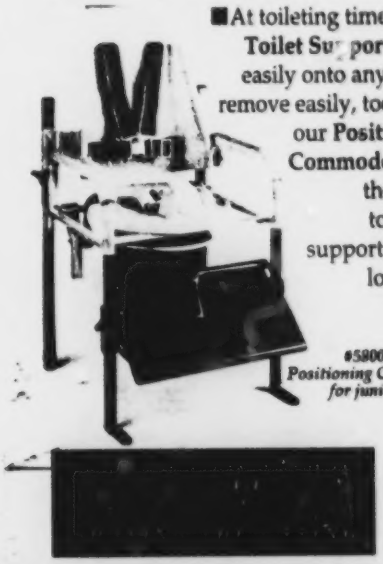

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Biting Problem

C.H. (November 1995) is the mother of 18-month-old Ryan, who has brain stem hypoplasia, myoclonic seizures, mild cerebral palsy and profound mental retardation. Ryan also has a very strong bite reflex and a tendency to put his right hand into his mouth. C.H. wanted to find a way to keep Ryan from biting his fingers that would not involve restricting his arm movement.

In the May 1996 issue, V.V. and R.V. wrote to offer the solution that worked for their son, Michael. They place a tall plastic drinking cup over Michael's hand and hold it in place with a large white sock. This allows Michael to bite at his hand without hurting himself.

My daughter has a severe visual impairment due to retinopathy of prematurity. She has the habit, not uncommon in children who are blind, of pushing one fist into her eye. We tried using an arm splint to keep her fist away from her eye, but it kept her from exploring objects by bringing them very close to her eyes and mouth.

I came up with a device that would restrict her from bending her elbow completely without restricting her ability to manipulate and explore objects. You can construct this device using the following items: a Morton's salt box, a 5/8-inch x 26-inch strip of elastic and a 5/8-inch by one-and-a-half-inch piece of Velcro.

First, remove the ends of the salt box. Approximately one-half inch below one of the open ends, use a hole punch to make two holes across from each other. Cut the elastic into two strips—one 10 inches long, the other 16 inches long. Sew the Velcro to an end of each length of elastic. Tie the opposite ends of the elastic though the holes you made in the salt box (and place the knots on the outside of the cylinder so they will not rub on the child's arm). Slip the child's arm through the salt box so the elastic straps are near the child's underarm. Bring the longer length of elastic across the child's chest with the shorter piece going around his or her back. Attach the two ends with the Velcro. You can easily adjust the length of elastic by redoing the knots.

As a child's arm grows, an oatmeal box may work better. We decorated ours by wrapping it with contact paper in a juvenile design. The child wearing this device can bend her arm enough to manipulate objects close to her face, but cannot bite her hand or push her fist into her eye.

H.S., South Carolina

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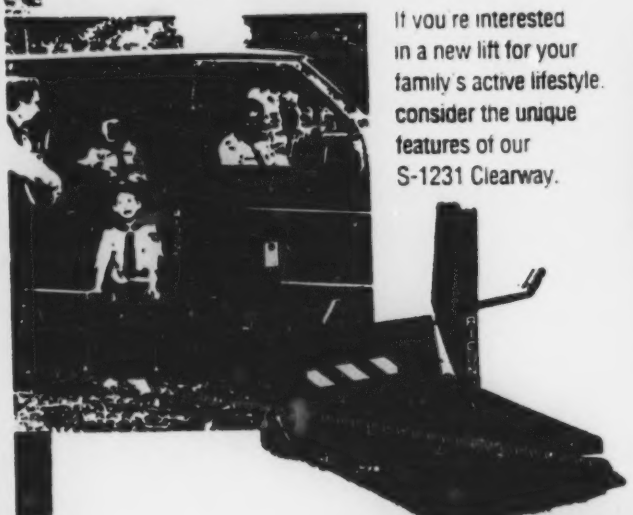

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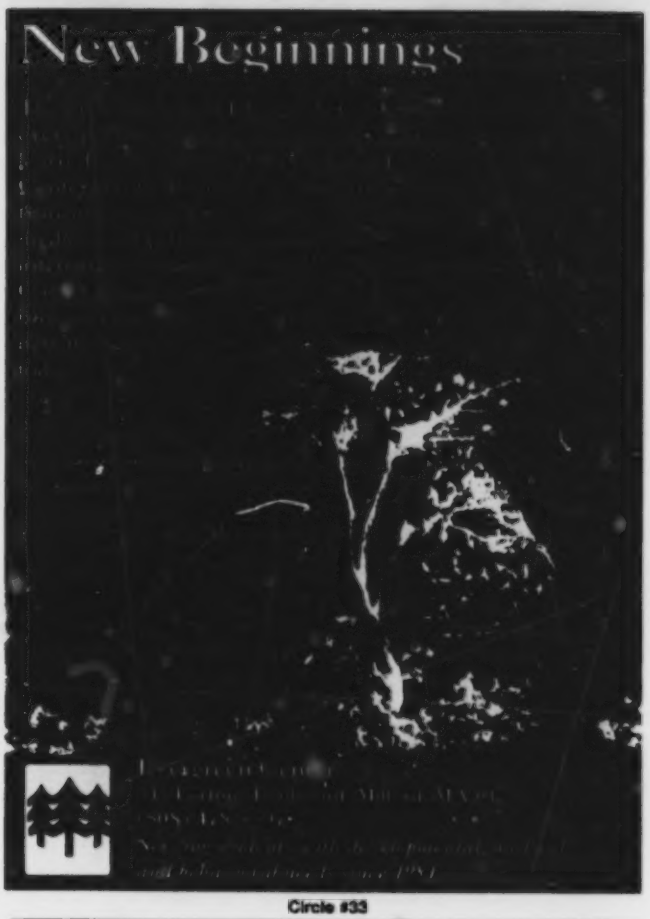

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Circle #31

Familiar Faces

The Halley boys, (from left) **Graham, Ross** and **Derek,** are always the first to grab Daddy's unoccupied hammock. It's the perfect spot to "hang out" and enjoy a lazy summer afternoon. Graham, 2, and Derek, 4, have an unidentified type of leukodystrophy; their mom calls six-year-old Ross a "terrific big brother." Derek attends preschool and especially enjoys hitting the swimming pool when it's time for his aquatherapy sessions. Graham is enrolled in an early intervention program, where his big smile and infectious laugh have earned him the nickname "goofy Grahamie." Ross, Derek and Graham live with their parents, Melanie and Ian, in California, Maryland.

It was a proud day for 13-year-old **Susan Cheney** when she was named Scholar of the Week by Montgomery, Alabama, television station WAKA. The award was presented to Susan by WAKA news director Bill "Tell" Zortman at a ceremony at her school, Dozier Elementary. Susan was nominated for the award by her sixth-grade teacher, Susan Odle, who wrote, "Susan's accomplishments may not seem extraordinary... [but she] has cerebral palsy, is non-verbal and uses an electric wheelchair. She uses a computer to do her school work and talk to her friends. With the help of her aide, Kay Smith, Susan has advanced through elementary school at the same rate as her peers, while attending all regular classes. Susan is a hard-working, determined young lady." Susan lives with her parents, Bob and Marilyn, in Hope Hull, Alabama, and now attends Brewbaker Junior High School.

Would you like to share a favorite candid snapshot or slide *of your child and/or family with other readers of* EXCEPTIONAL PARENT*? Send it to: Readers' Photos,* EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517. (Sorry, photos cannot be returned.) On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

It sure doesn't seem like work! **Claire Therese Turon,** 17 months, enjoys her oral-motor therapy sessions, in which she gets to explore and play with lots of different foods. And when it's time to clean up, Claire is more than willing to take care of the mess on her fingers, but the rest is up to Mom! Claire, who has Down syndrome, lives in Beach Park, Illinois, with big brothers Michael, 8, and Nicholas, 5, and parents Mary and Mark.

Jerrick Nicholas Inaldo and his dad, **Perry,** may call San Francisco home, but some local sights—like the view of the Golden Gate Bridge on a clear autumn day—never get old. When not out on the town with his dad and mom, Jerilyn, three-year-old Jerrick, better known as "Nicky," keeps up with a busy schedule that includes games of hide and seek, scribbling, playing the piano, listening to music and attending preschool at Loma Chica School in Pacifica, California. Nicky has cerebral palsy and microcephaly.

Four-year-old **Jamal Shaquille Ira Moore** (front center) is surrounded and supported by loving friends and family (clockwise from lower left) playmate **Desi Bailey,** aunt **Miya Moore,** mom **Darlera Moore,** aunt **Adriare Moore** and grandmother **Wanda Moore.** Jamal has tuberous sclerosis (TS), a genetic disorder that can cause seizures, mental retardation, tumors and white spots on the skin. Jamal's TS affects his brain, heart and skin; he also has a difficult-to-control seizure disorder and expressive language delays. Jamal's mother, Darlera, describes him as "almost always happy, with a hug, a kiss and a big smile for everyone who comes his way." She writes, "I hope Jamal's positive attitude gives everyone the message that even though we all have 'trials and tribulations,' we can still show love and help keep one another going." Jamal and his mom live in Dover, Delaware.

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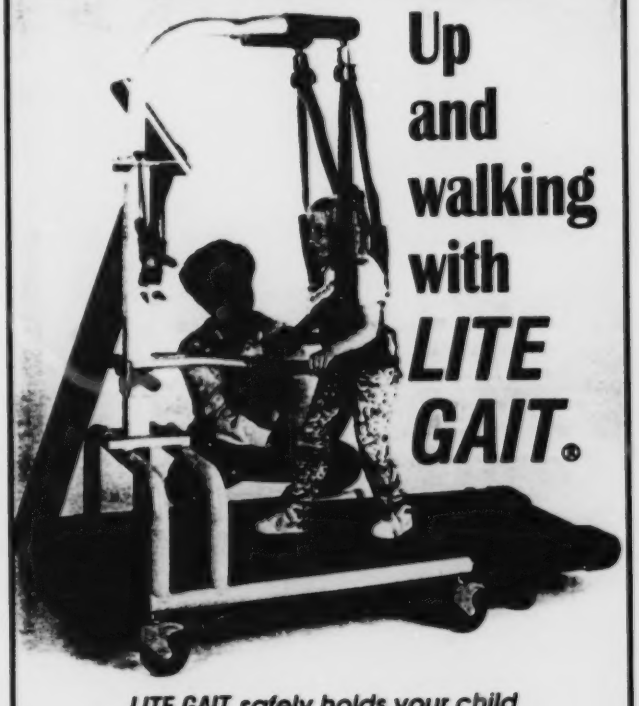

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Circle #42

Penney's Golden Rule

September means back to school, back to routine, and—inevitably—back to the stores! America shops in the fall to adapt to a new season, plan for the future, and restore the balance that summer discombobulates. The stores that we return to again and again are those that understand us as customers: our tastes, our styles, our budgets. We renew our wardrobes, our homes, our sense of community.

JCPenney is a dedicated partner with America's communities. This philosophy was established with James Cash Penney's first store, aptly—and purposely—named The Golden Rule. The Penney Idea, established with the emporium named for its founder, was set in 1913:

- To serve the public as nearly as we can to its complete satisfaction;
- To expect for the services we render a fair remuneration, and not all the profit the traffic will bear;
- To do all in our power to pack the customer's dollar full of value, quality and satisfaction;
- To continue to train ourselves and our associates so that the service we give will be more and more intelligently performed;
- To improve constantly the human factor in our business;
- To reward men and women in our organization through participation in what the business produces;
- To test our every policy method and act in this wise: "Does it square with what is right and just?"

JCPenney

In its commitment to community, JCPenney believes that abilities, not disabilities, determine a person's potential. It has displayed a consistent commitment—in its boardroom, offices, stores and communities—to give ability a chance. Its corporate leadership actively promotes the equality, dignity and independence of people—customers and employees—with disabilities.

JCPenney aims to comply not only with the letter of the Americans with Disabilities Act (ADA), but with its spirit as well. The company's practices live up to this policy. All stores are being reminded to meet ADA standards for automatic door openers and wide aisles, and special "Serving Customers With Disabilities" training is being given to all sales associates. Penney associates (employees) are personally committed to customer accommodation. In Florida locations, for example, store managers made sure furnishings and displays were user-friendly by taking to wheelchairs for a day and testing out their own stores.

JCPenney advertising continually features persons with disabilities, whether in newspaper inserts or catalogs. The Special Needs Catalog speaks directly to this valued market.

For its associates, JCPenney believes that disabilities should not be a barrier to high achievement. Through hiring, training and promotion policies and practices, abilities, not disabilities, determine a person's potential.

JCPenney also strives to extend its Golden Rule into store communities to promote equal access. The company is a driving force in its hometown's annual job fair held by the Dallas Mayor's Committee for Employment of People with Disabilities. It also sponsors the popular Ladies Professional Golf Association Skins Game which sent more than $500,000 this year to the Easter Seal Society of North Texas. This group helps families shoulder the financial burden created by therapy costs and special equipment their children need.

PHOTO COURTESY JCPENNEY FROM ITS FALL/WINTER CATALOG

PHOTO COURTESY OF JCPENNEY AND THE EASTER SEAL SOCIETY OF NORTH TEXAS FOR THE LADIES PROFESSIONAL GOLF ASSOCIATION SKINS GAME

JCPenney's association with the National Organization on Disability (NOD) takes its outreach one step further to promote full participation of America's citizens with disabilities in all aspects of life. Since 1985, JCPenney has contributed more than $1 million to NOD for community and professional membership groups to support programs that benefit people with disabilities.

JCPenney's policies, practices and programs aim at breaking attitude as well as access barriers. They are, indeed, the heritage of the founder's philosophy of The Golden Rule. Chairman W. R. Howell explains it well: "In opening the doors of opportunity at JCPenney, we are serving the best interest of our business."

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

801

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JCPenney

Fashion is Always in Style

Circle #92

Sixteen-year-old Michela Alioto (right front) attends a Christmas dance with friends at her school, Convent of the Sacred Heart high school.

Michela Alioto

Running for Congress

Michela Alioto, 28, won the Democratic nomination to run for California's First Congressional District seat in the U.S. House of Representatives. Alioto, the oldest of four siblings, grew up in San Francisco and is a 1992 graduate of UCLA, where she majored in anthropology. At the age of 13, Alioto broke her back in a ski lift accident; she now uses a wheelchair.

Alioto, who says she has always wanted to be involved in politics, spent two and a half years working for Vice President Al Gore as a member of his domestic policy staff before deciding to run for Congress. As EXCEPTIONAL PARENT *was going to press, polls showed the race between Alioto and her Republican opponent, incumbent Frank Rigg, too close to call. The following was adapted from an interview between Alioto and* EXCEPTIONAL PARENT *editorial intern Meredith Gerson.*

I was only 13 when my accident occurred, and children that age are pretty resilient. The accident had some negative aspects, but most of the things that came out of it were good. It made everyone in my family stronger; I know it made me stronger. It's given me opportunities to reach out to people I otherwise wouldn't have had. I have done different things with my life because of it.

I broke my back in April. I was only in the hospital for two and a half months, so during the summer, I was able to make up the school I'd missed. My school had not been wheelchair-accessible previously, but they put in ramps before I returned.

I had good doctors, but I took what they said with a grain of salt. When they told me I wasn't going to walk again, I said, "yeah right." When they told me I wasn't going to play sports, I said, "yeah right." When they told me I may not go to college, I said, "yeah, whatever." I don't think anyone in my family believed the doctors. We still don't.

My parents raised me to believe that our lives are not just about ourselves but about giving something back by helping others. My parents reacted to my accident by co-founding an organization called the American Paralysis Association, which raises money for neurological research.

The accident really didn't affect me socially. I had my group of friends before the accident, and when I got hurt, they were still my friends. I ran for student body president from the hospital. I wrote my speeches and had friends give them for me. We made signs, and my friends brought them to school and hung them up. And I won the election. I think it's important to tell kids, "You know, you can get over anything. You just need to keep going."

Building bridges

I've always wanted to be involved in politics. I've fought for years not only to make sure I'm treated well, but to make sure other people are treated well, too. I think everyone should have a chance.

I spent several years working for Vice President Gore and watching the Republican Congress take over. It didn't

continued on page 40

Michela (front right) joins supporters in front of her campaign headquarters in Napa, California.

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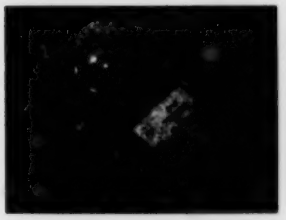

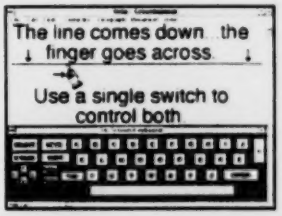

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Circle #74

ROLE MODELS

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take long for me to realize that Congress was not moving in the right direction. So I left my job at the White House to run for the House seat representing my home district.

I would like to see young people take control of their futures and push the country in the right direction. We should make education a national priority, and we need to put money into educational programs that promote independence and individual empowerment.

I think the biggest challenge for the disability community is visibility. Our greatest disability is other people's ignorance and fears. We are fortunate to have the ADA and the Rehabilitation Act, but it is our responsibility to make sure these laws are implemented. Thurgood Marshall said, "the legal system can force open doors and even knock down walls, but it can not build bridges." I believe *we* need to build those bridges; we need to remind people that we're all in this together.

This is why I believe in inclusion in our educational system. It's not only important for kids with disabilities but also for the other children. In the same way, disability-related issues need to be integrated into every piece of legislation we put out there. Whether we're talking about transportation, education or health care, everything we do should relate to people both with and without disabilities.

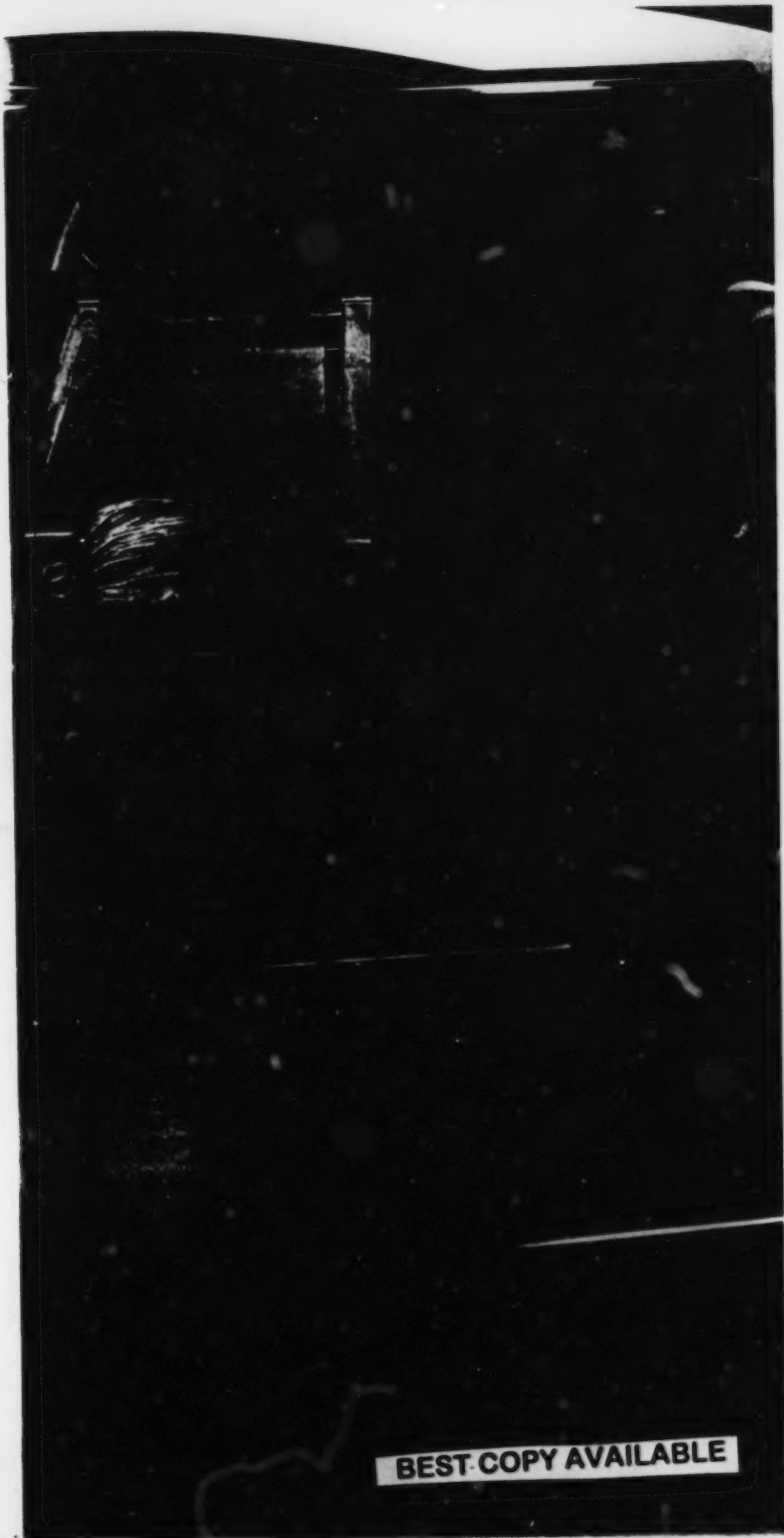
We need to show society that it's not bad to have a disability. We can do this by simply leading our lives—getting up in the morning, going out and doing things, making sure we don't let society make our disabilities an issue.

Choosing fights

People with disabilities drive cars, have college degrees, hold down jobs and pay taxes, but we still have to fight so many negative stereotypes every day. For example, I get really mad when people do things like push my wheelchair. When I was living in D.C., it happened a lot. I'd be going up a hill, and someone would come up behind me and start pushing. My first reaction was always to put my thumbs right into the brake. After all, I had been moving myself along just fine. I'd get really mad; I'd turn around and go, "Stop! What are you doing?"

Someone once said, "But Michela, they're just trying to be nice." And I thought, yeah, they're just trying to be nice, but does kindness justify ignorance? Something done with good intentions can still come off as offensive and patronizing. After a while, I just cut the push bars off the back of my wheelchair.

I've come to realize that it is important to pick your fights carefully. You can't get mad at everybody. If there are one or two steps going into a little restaurant, you have to let it go; but if it's a major grocery store chain, you sue 'em. I can't consume myself with all the bad things out there. Negativity has no place in my life. I can't walk, but that doesn't mean I can't do everything else. Not being able to walk is a hassle, but it doesn't affect the quality of my life. It just makes things a bit more difficult. **EP**



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My Daughter, My Teacher

by Mary Jane Kitchens

Thanks to Mom's face-painting skills, (from left) Jacob, Joshua and Mandy make perfect clowns.

As much as we parents would like to believe that we are wise, experienced adults charged with the important task of imparting our vast knowledge to our children, it is often, in fact, our children who teach us. Day after day, I am amazed by how many things my children teach me. Today's lesson was particularly significant.

When my little girl, Amanda, was born almost six years ago with several congenital anomalies, I was completely and utterly overwhelmed. To those around me, I appeared strong and in control, but inside I was filled with shock, disbelief, fear and anger.

Mandy's condition, VACTERL association, involved a number of medical problems, including kidney and spinal defects, but I was so concerned with Mandy's arms that her other conditions seemed to pale in comparison. She was born with a very short left arm, a very small left hand with only two fingers and a short right arm with no thumb or radius (the long bone on the thumb side of the forearm that would have normally extended from elbow to wrist). I was devastated by thoughts of my beautiful little girl being ridiculed and ostracized because of her physical differences. Would she have friends? Would she date? Would she go to the prom? Would she be able to marry and have children?

What about the rest of the world?

From a very early age, Mandy showed such spunk and determination that I learned not to worry about her physical abilities. Whenever I tried to "teach" her to do something, she always found a way to do it better. I soon realized that the best way to help my daughter was not to help, unless she asked.

Eventually, I rarely even noticed Mandy's short arms, but I knew they were the first thing other people saw. I saw Mandy as the wonderful person she was—loving, smart, funny and beautiful. But what about the rest of the world? How were they going to treat my child?

I loved my daughter with every fiber of my being, and I wanted to protect her. I wanted to protect her so badly that I considered homeschooling. Mandy had been around other children before, but I had always been there to help her handle their questions and stares. At school, she would be on her own. She's not ready, I kept telling myself. They'll tear her apart and break her spirit.

Letting go

But Mandy was eager to join her big brother at school. She wanted to make friends and

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Oblivious to her mother's worries, Mandy was all smiles on her first day of kindergarten. She and brother, Joshua (left), attend the Eberwhite Elementary School in Ann Arbor.

At school, Mandy quickly made friends, including best friend Erin Walker (left). "They hit it off during play time and have been best friends ever since," writes Mandy's mom, Mary Jane. Later, the girls discovered they share the same birthday.

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play at their houses; she looked forward to birthday parties and all the other fun activities her big brother got to do.

I really had no choice but to let her go. I prepared her as best as I could, trying to explain what might happen and to provide her with responses to the questions other children might ask. Mandy's first day of school was very exciting for her, but it was the hardest day of my entire life.

When we got to the school, I brought Mandy to her classroom and waited with her while the other children started to arrive. Almost immediately, they began to gather around her, trying to touch her arms, innocently asking, "What happened?" and "Does it hurt?"

My stomach tied in knots. I wanted to grab Mandy, run out the door as fast as I could and never return. I prepared myself for the tears I was sure she would shed and knelt down next to her so I could help explain her differences. But I never got the chance. My daughter simply announced, "That's just the way I was born."

That statement was all that was needed. The children began talking about other things, and it was clear that Mandy had things under control. Still, I told myself, they are all very young. Acceptance won't always be this easy. I walked out of the school sobbing because I was so proud of my daughter, but also because I was still so very afraid for her.

Growing and learning

Mandy's first year of school went well. A few times, Mandy seemed bothered by people's questions—mostly, I think, because she tired of them—but for the most part, her school experience was very positive. She made lots of friends and had many invitations for play dates. Her active social life soon grew to include Daisy Girl Scouts and therapeutic horseback riding lessons.

But I still worried. I wondered if Mandy realized the obstacles she would have to face in the future. Maybe we had loved her so much that we had wrongly sheltered her from the attitudes of others. I feared that she didn't understand that her arms would always be the way they are—that they wouldn't one day "finish" growing. Until today.

Mandy stood in front of the stereo this morning, looking at her reflection

continued on page 36

Rev it up! Mandy is raring to go on the back of her younger brother Jacob's motorcycle.

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continued from page 34

in the glass door. I didn't really think anything of it: she had seen her reflection many times before. This time, however, she started crying. When I asked why she was upset, she explained that she was afraid that when she grew up, she would look "silly" with her "little arms."

I struggled to keep my composure. I hugged her and told her it would be okay. I told her she could do just about anything she wanted to. I babbled on and on about how how her small arms wouldn't stop her from fulfilling her dreams. Then, finally, I stopped talking long enough to actually listen to her, and I realized what she meant.

Mandy thought her arms wouldn't grow in proportion to the rest of her body! So I explained that they would. I showed her some of her baby pictures, pointing out that as she'd gotten bigger, her arms had gotten bigger as well. "And as you continue to grow," I said, "your arms will grow along with the rest of your body." I hesitated, and then added, "But your left arm will not grow as long as your right, and you won't grow any more fingers."

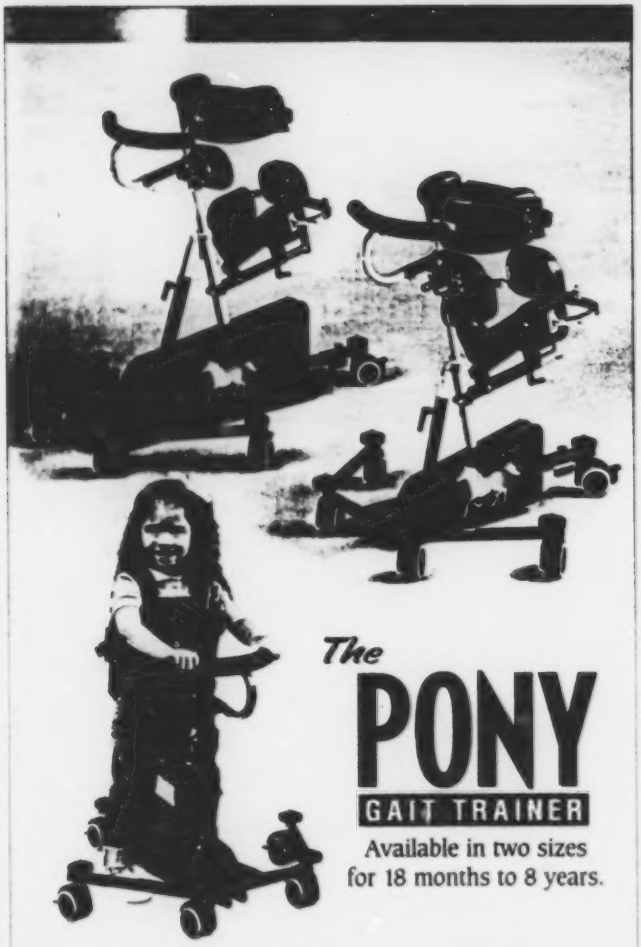
Mandy straightened up and proudly said, "Good! I don't want any more fingers. I like my hands just the way they are!"

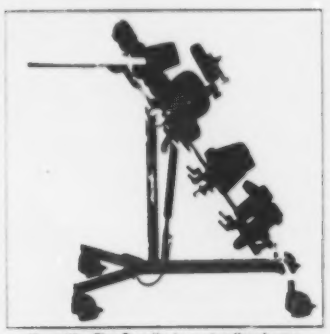
Thank you, Mandy, for teaching me what you knew all along. I don't need to worry about you or pity you. I will save my pity for those who don't know how to accept differences and who might miss out on knowing someone as beautiful as you because of their own misconceptions and attitudes. Like me—before today—they are the ones with the problem, not you. **EP**

Mary Jane Kitchens lives in Ann Arbor, Michigan with her husband, David, daughter Mandy, 6, and sons Joshua, 8, and Jacob, 4. She works part-time, volunteers at her children's school and assists with Mandy's Daisy Girl Scout troop. David works as a glass installer at Brad's Mobile Auto Glass. Mandy, who has VACTERL association, attends morning kindergarten at Eberwhite Elementary School in Ann Arbor. She loves to draw, swing on her swing set and cuddle with Dancer, her cocker spaniel.

VACTERL association is an acronym for several congenital anomalies that often appear together: (V)ertebral anomalies, (A)nal atresia, (C)ardiac anomalies, (T)racheo(E)sophageal fistula, (R)enal anomalies, radial dysplasia and other (L)imb anomalies. The TEF/VATER Support Network (c/o Greg and Terri, 15301 Grey Fox Rd., Upper Marlboro, MD 20772; 301/952-6837) provides information and support to families of children with VACTERL association and/or birth defects associated with the esophagus (the tube that carries food from the throat to the stomach). The organization offers parent matching services and publishes a newsletter and family directory.

811

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Circle #76

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The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

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Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
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(413) 528-2523

812

Circle #79

A Letter from the March of Dimes

Teresa Wolding's March 1996 *Point of View*—"So... Why Was *Your* Baby Born Early?"—generated many letters from readers who agreed with Wolding that public education efforts linking prematurity and birth defects to maternal substance abuse or inadequate prenatal care was leading to "a growing intolerance directed at the families of children with disabilities." The March of Dimes, a leader in the effort to reduce the incidence of congenital disabilities through public education, also received a great deal of mail on this issue. Here is their response:

March of Dimes
Birth Defects Foundation
[illegible]

July 31, 1996

Stanley D. Klein, Ph.D.
Editor in Chief
Exceptional Parent
209 Harvard Street, Suite 303
Brookline, MA 02146

Dear Dr. Klein:

Thank you for the opportunity to respond to your readers' letters. We regret that one particular set of our advertising inadvertently has offended some mothers who have done everything they could to have a healthy baby. Our goal was to help women reduce their risks based on the latest available scientific information. While the ads some of your readers objected to are no longer in active use, they were targeted to women who may engage in unhealthy behaviors during pregnancy.

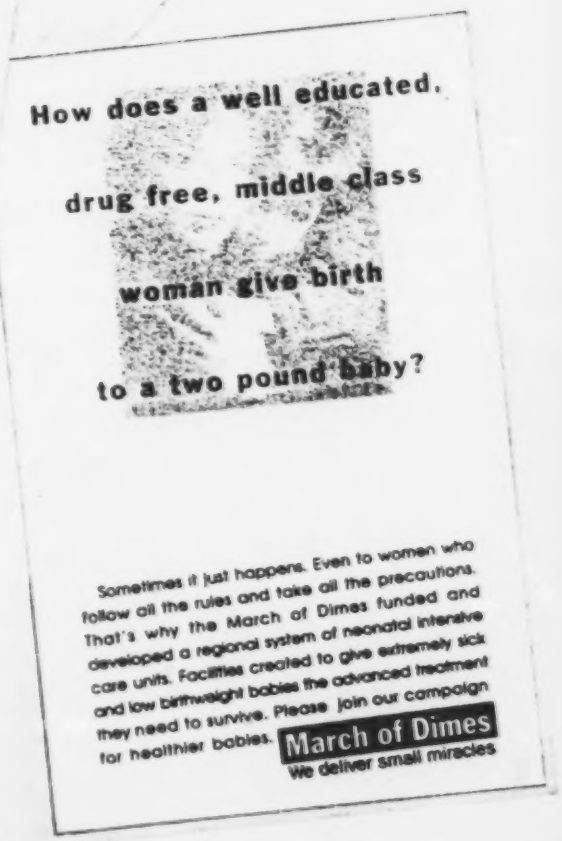
When providing information about not smoking or drinking during pregnancy, we never intended to imply that any one of these actions is linked to all preterm births or infant health problems. One of our ads also dealt with the fact that many preterm deliveries occur for unknown reasons (see attached ad).

None of the letters and phone calls we received regarding our prior advertising asked us to stop giving important health information to prospective parents, but instead underscored the importance of continuing to do so in a more sensitive manner. The comments and feedback from *Exceptional Parent* readers are very helpful to us as we plan new educational efforts.

The challenges we face in meeting our mission to reduce birth defects are significant. Only by working together can we ensure that consistent progress will continue to be made.

Sincerely,

Mary Giammarino
Vice President, Communications


How does a well educated,
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Sometimes it just happens. Even to women who follow all the rules and take all the precautions. That's why the March of Dimes funded and developed a regional system of neonatal intensive care units. Facilities created to give extremely sick and low birthweight babies the advanced treatment they need to survive. Please join our campaign for healthier babies.
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Circle #87

EDUCATION

Defining Inclusion

by Diane Sydoriak

"Mainstreaming," "integration," "regular education initiative," "least restrictive environment," "inclusion" and "full inclusion"—these are all terms that have been used to convey the meaning and intent of special education. Unfortunately, many people use these terms without a consensus regarding what they mean and how they should be translated into action. This has led to an emotional dialogue among parents, educators and other professionals involved in the implementation of special education services for children with disabilities.

Today, 20 years after the passage of Public Law 94-142, the Education for all Handicapped Children Act, now known as the Individuals with Disabilities Education Act (IDEA), the debate continues: *What is special education?* and *Where is it to be provided?* Defining the term "inclusion" may help us begin to answer these questions.

A working definition

In Arkansas, where I am Associate Director of the state's Special Education Unit within the Department of Education, we believe that "inclusion" is an underlying assumption of the "least restrictive environment" (LRE) requirements that have been part of special education law for nearly two decades. Inclusion implies active social membership of individuals with disabilities in their classes or communities.

Inclusion does not represent a legal requirement that every child be educated in the same way or in the same place. In fact, the word "inclusion" is never used in federal regulations. Inclusion is not a place or a placement. Inclusion is a philosophy regarding the manner in which a free, appropriate, public education is to be provided to children with disabilities.

The concept of inclusion means much more than a child with disabilities simply spending a full day in a regular classroom. Inclusion implies being included. "To include" means "to consider as a part of a whole." Thus, "inclusion" means "to participate in and be a part of." The meaning of "participation" and "being a part of" may vary for different students—even for students with similar disabilities—and will depend in no small part on the services and service-delivery settings an individual student needs to benefit from his or her IEP (individualized education program).

From this working definition of inclusion follows a commitment to educating children with disabilities, to the maximum extent possible, alongside children without disabilities and within the regular classroom. Arkansas law further requires that "impediments to learning and to the normal functioning of children with disabilities shall be overcome, when possible, by the provision of supplementary aids and services rather than by separate schooling for children with disabilities."

The key element in these statutes is the presumption that the child with disabilities should be in the regular school and, more specifically, in regular classes. With that assumption, Arkansas statutes state that the child is to be removed from the regular classroom *"only when,* even with supplementary aids and services, the child's education cannot be accomplished satisfactorily." It is important to note that resource room services are considered to be part of the "supplementary aids and services" that could be used to help a student with disabilities remain in the regular school environment.

If students with disabilities are presumed to belong in the regular school environment, the question to be answered for each student becomes: "What supplementary aids and services does this student need to implement and benefit from his or her IEP?" But there is a more simplified way to phrase the question—"What will it take to avoid exclusion?"

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Santana High School • Santee, California

At Santana High School, students with and without disabilities enjoy lunch and the California sunshine together.

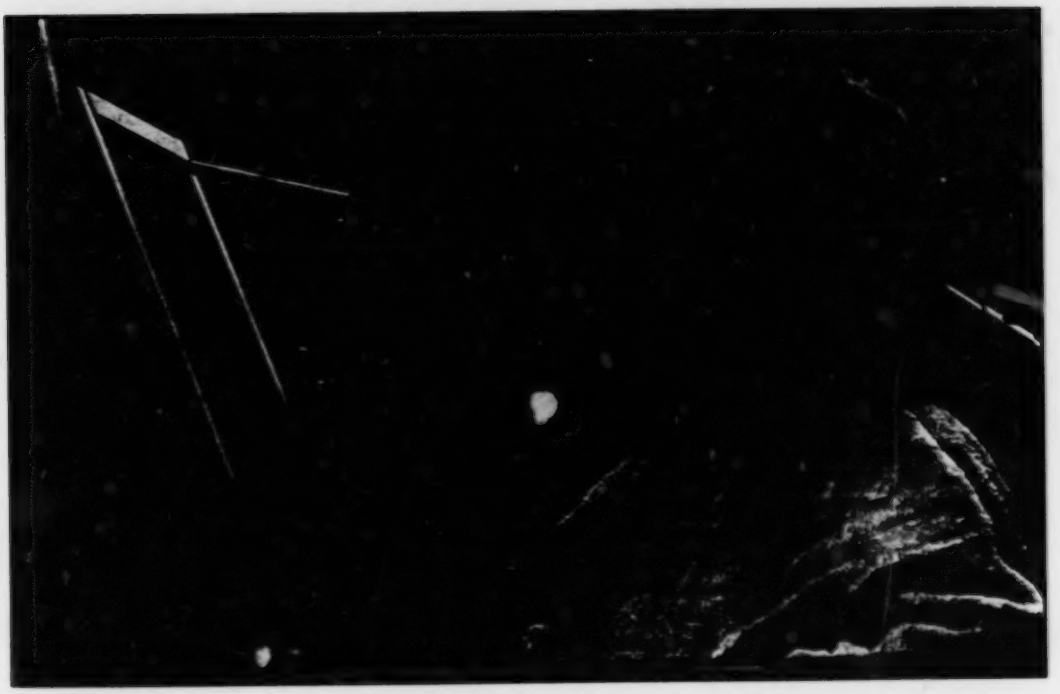
Santana High School's inclusion of students with disabilities in regular education classes has been a community-wide effort. In addition to the full support of district administrators, a partnership with San Diego State University provides staff development opportunities and guidance in curriculum development. Parents have also assumed more active roles.

When inclusive education began here in 1993, it was part of a larger restructuring of the entire curriculum. The staff also implemented a new schedule that provided ample time for regular and special education teachers to work together and plan innovative strategies to address diverse learning styles. Although assignments are sometimes modified for special learning needs, all students in a class study the same material.

Inclusion at Santana High means more than just incorporating students with disabilities in regular classes; it also means including them in the overall learning environment. LaSheika Little, a junior at Santana, says that inclusive education has benefited all students: "We have learned to get to know one another better and therefore build better understandings and friendships...The point I'm trying to make is that inclusion works!"

1996 EDUCATION AWARD

815



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Spring Time by Amy Neubauer

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Because IEPs must be based on the individual needs of students with disabilities, and because services and service settings must be selected to implement the IEP in a way that will benefit the student, the full continuum of services must be available. We would be wrong to make a wholesale decision that all students with a certain disability should be in a self-contained educational or residential setting. But it would be an equally serious error to say that all students with disabilities should remain in regular classrooms with no other service settings available through which the IEP could be more appropriately implemented. Inclusion is not all or nothing. Inclusion is the result of appropriately implementing a student's IEP and, at the same time, giving the student the opportunity to participate, to the maximum extent possible, in the regular educational environment with his or her peers who do not have disabilities.

Reaching consensus

Although the inclusion of students with disabilities has become one of the most hotly contested reform efforts facing educators today, people on both sides of the argument agree on certain tenets. The National Association of State Boards of Education (NASBE) has identified the following areas of consensus:

- *Planning:* Inclusion is most effective when students with special needs are placed in general education classrooms after adequate planning. Inclusion does not mean unilateral changes in students' placements without appropriate preparation.
- *Creativity:* There are no "Ten Commandments for Inclusion" that have been handed down from on high. Rather, educators, parents and others must continue to work creatively and boldly to find ways to implement inclusion at the state, district, building and classroom levels.
- *Dealing with the stress of change:* At its core, inclusion means change, and change is always stressful and highly personal. Bringing students with disabilities out of the "safe haven" of separate facilities and into the challenging climate of a local school is stressful to everyone involved.

Inclusion reflects the greater society where people with and without disabilities work and live together. Inclusion seeks to create a society where we are not judged by the condition of our body or intellect, but by the content of our character. In this way, inclusion serves as a bridge for present and future understanding between and among people with and without disabilities. **EP**

Diane Sydoriak, Ed.D., is Associate Director of the Arkansas Department of Education, Special Education Unit and current president of the National Association of State Directors of Special Education (NASDSE). A longer version of this article was published in ON-LINE, *the newsletter of the Arkansas Special Education Resource Center, during the 1994–95 school year.*

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EDUCATION

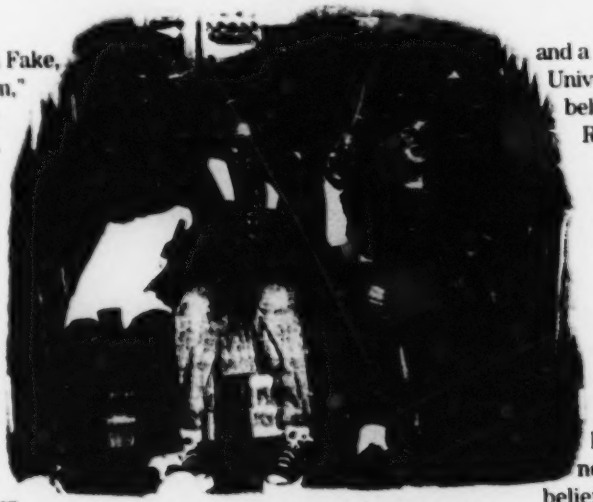
Why Does Samantha Act That Way?

Positive behavioral support leads to successful inclusion.

by The Family Connection staff, Gigi DeVault, Cathy Krug & Susan Fake

Twelve-year-old Samantha Fake, affectionately called "Sam," likes to write poetry, use computers and listen to music. Her teachers describe her as sociable, inquisitive and creative. Her school principal calls her a model student.

It may be hard to imagine that three years ago, many people might have considered Samantha a child who did not "belong" in regular classes. Sam, who has autism and moderate speech disabilities, often ran out of her third-grade classroom, damaging other students' belongings and school property on the way. When her educational aide or another adult intervened to prevent these flights or to escort her back to class, she fought back by biting, scratching, hitting, kicking and pulling hair. Sam's parents, Susan and Ken, lived every day on edge—always waiting for "the phone call" from school, always wondering how they would manage to drop everything and comply with the request to take Sam home when the call came.



Samantha Fake (far right) is supported in school by a "circle of friends" that includes (from left) Merisa Magadia, Fernanda Gomez and Angela Nelson.

So how did Samantha, the third-grader who did not belong, become a student who was genuinely welcomed? A new program was started—one that worked: positive behavioral support.

A vision for inclusion

Near the end of Sam's third-grade year, Sam's "action group"—a group that included Sam, her parents, her teachers, her occupational and speech therapists and a behavioral support team from the University of Washington (see sidebar below)—met for the first time.

Realizing that Sam would not be able to remain in a regular classroom setting unless her behavior changed dramatically, the group felt a sense of urgency.

They began with the common belief that Sam could be successful in a regular school and classroom setting. They were able to envision Sam behaving positively with sufficient support to meet her unique learning and social needs. They also reaffirmed a belief that everyone involved would be able to work together to make necessary and consistent changes in Sam's environment.

Getting to "why"

With positive behavioral support, the emphasis is on creating responsive environments—not on "fixing" the individual. Positive behavioral support begins with the assumption that repeated inappropriate behaviors occur for a reason. For example, hair pulling and biting are dangerous behaviors, but they may be

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Positive Behavioral Support Teams

Twenty-one states have positive behavioral support teams similar to the one that assisted Sam and her family. Trained by the Rehabilitation Research and Training Center on Positive Behavioral Support at the University of Oregon, these teams, consisting of family members and professionals, travel across their respective states providing training in local communities. The training typically involves 20 hours of instruction in implementing positive behavioral support programs for individuals with developmental disabilities and serious behavioral challenges. Following the training period, the team remains available to provide advice and assistance. Though programs and services vary from state to state, this training never involves any out-of-pocket expenses for families.

The Family Connection can provide families with more specific information on teams in particular states. In addition, the Family Connection staff can help parents in any state locate local resources for implementing positive behavioral support programs. For more information, contact The Family Connection, Beach Center on Families and Disability, University of Kansas, 3111 Haworth Hall, Lawrence, KS 66045; (800) 854-4938, voice (use 800-number only for calls regarding behavioral issues); (913) 864-7600, voice/TTY; (913) 864-7605, fax; family@dole.lsi.ukans.edu, e-mail.

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an individual's only means of expressing fear, confusion or unhappiness.

A good behavioral support plan begins with a "functional assessment"—an attempt to make sense of inappropriate behaviors by looking beyond their inappropriateness to examine the purposes they may serve. Sam's behavioral support team began this process by talking with the people who knew Sam best and by directly observing her behavior in a variety of situations. This helped them come up with detailed descriptions of her inappropriate behaviors (bolting from the classroom and fighting attempts to return her to class) and the circumstances that typically preceded and followed each episode. This information allowed the team to make predictions about when these behaviors would be most likely to occur—predictions that could be tested through further observation.

The team observed that Sam's problem behaviors often began when she was engaged in academic seat work—usually spelling, writing or math, subjects she found especially difficult. Sometimes, the behaviors even occurred when Sam simply had reason to anticipate such work. Sam's attempts to leave the classroom always resulted in attention from adults—most notably, her educational aide, whose attention Sam especially valued.

The team hypothesized that Sam's inappropriate behavior was associated with a desire both to avoid difficult school work and to engage the attention of a valued adult. To test that theory, the team arranged to observe her several times in four different situations: (1) playing alone, (2) playing with someone she liked, (3) anticipating or doing a favorite academic task and (4) anticipating or doing spelling, writing or math seat work. Based on their hypothesis, the team predicted they would see Sam's problem behaviors only in the fourth situation.

This prediction was borne out by the team's observations. Sam seemed to be using problem behaviors to express sentiments she had difficulty communicating verbally—messages like "Don't take me back to the classroom" or "Pay attention to me!" Running from the

Samantha, 11, makes her First Communion in April 1995.

classroom allowed Sam to escape difficult and frustrating tasks while gaining the attention of valued people.

For example, one observed episode occurred when Sam and her classmates were working on a math worksheet involving the concept of coin equivalence. After trying several problems, Sam said, "This is too hard." When her aide urged her to continue, Sam broke her pencil in half, swept the worksheet off her desk, pushed nearby materials off a shelf, and then ran out of the room. When the aide did not immediately follow, Sam returned to the doorway and asked, "Are you going? Will you come?"

Further assessment showed that these episodes were even more likely to occur when too many "setting events" (events that seem to influence or lead to certain behaviors)—lack of sleep, staff absences or other departures from routine—"snowballed" during a particular time period. In addition, as much as 30 percent of Sam's physically aggressive behavior occurred as a reaction to restraint or unwanted physical assistance to go to or return to class.

The functional assessment also gave Sam's team a lot of information about what she appeared to need and want. For example, Sam sometimes needed to retreat from the demands and heavy sensory input of the classroom environment. But she also longed for social connection; much of her considerable energy and creativity seemed devoted to gaining the attention of people she liked.

Sam hits downtown Seattle to do her holiday shopping with Mom Susan.

Organizing for success

A good functional assessment provides the knowledge needed to modify the environment in ways that should increase the likelihood of positive behaviors and decrease the probability of inappropriate behaviors. In Sam's case, this meant providing her with a consistent, predictable daily schedule that included many rich, rewarding, socially connected and preferred activities.

Sam's new schedule allowed her to take breaks from the demands of the classroom. Scheduled breaks included vocational activities such as photocopying in the school office and helping in the cafeteria. And when Sam needed an unscheduled break, she learned to ask for her "relaxation room." The relaxation room was not a place where Sam received attention, rather, it was a quiet, private space where she could be alone, sit in a beanbag chair and listen to calming audio tapes of her own choosing until she felt ready to return to the demands of her day.

The team also organized Sam's environment to give her a sense of control. It was clear that Sam—like other children—wanted to feel successful. However, she could not explain why some tasks were too difficult; nor could she specify approaches that would make tasks easier. But when given choices of different ways to accomplish a task, Sam *could* choose ways that worked for her.

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Learning new skills

A major goal of Sam's positive behavioral support plan was to help her learn new ways to influence her environment, skills that most of her peers had already mastered. She needed to learn how to communicate her needs and preferences and when necessary, ask for assistance.

Sam used her relaxation room primarily in the early stages of the plan's implementation. When her aide noticed behaviors similar to those that previously had escalated into flight and physical aggression, the aide would ask Sam if she wanted to go to the relaxation room. The question was an attempt to teach Sam that certain types of behavior (those associated with feelings of frustration and stress) could best be dealt with in the relaxation room and that Sam could communicate this need before things got out of hand.

After mastering the skill of asking for the relaxation room without being prompted, Sam did not seem to need the room as often. This is probably because having the ability to request the room gave her a sense of control that she previously had experienced only when her problem behaviors directed the course of events.

Figure One.

Sam also learned new ways to relate to her peers. For example, when she treated a classmate badly, the classmate was instructed to tell Sam that those actions had been upsetting. Sam, in turn, would be coached by her aide or classmates to apologize. The school's communication disorders specialist taught Sam to use the language of her peers to greet others, express positive statements and report displeasure. Most of this social-skills instruction took place in small groups of students; staff reinforced the practices during regular classroom activities.

Sam was given choices in academic work through the use of "goal sheets" (see figure 1) that allowed her to chose the task she would work on, the length of time she would work and the reward (or "special event") she would receive for meeting the goal. Sam was also given the responsibility of monitoring her own in-class behavior by filling out "self-management checklists."

Sam quickly learned to make check marks on both sheets when she met her goals. Typically, she was honest in her self-monitoring, motivated by the checks that showed a positive pattern and proud of her success at handling this responsibility. Sam shared her pride in this achievement with school staff and her family, receiving much praise for her successes.

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continued from page 45

Success becomes its own reward

To help make positive behavioral changes stick, Sam's team created a system for consistently rewarding appropriate behaviors. The team sought suggestions for tangible rewards from people who knew Sam best and from Sam herself. Samantha knew she could choose rewards for meeting goals; in fact, having such choices often seemed more important to her than the actual rewards.

Each day, Sam also received points for appropriate behavior, which accumulated over the course of the week and could be traded for weekend incentives such as trips to Dairy Queen or the local video store. As Sam continued to experience success, her pride of accomplishment became the most important reward. Tangible rewards were gradually reduced, and in time, none were necessary.

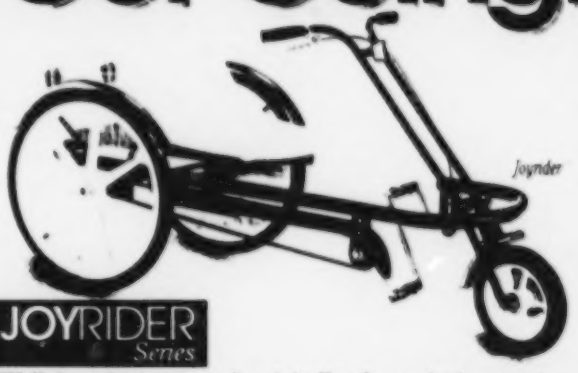
While it is important to reward positive behaviors, an effective positive behavioral support plan also carefully structures the environment so that rewards for inappropriate behaviors are removed. Previously, Sam's flights from class usually had the desired outcome—she received a great deal of adult attention, and her parents came to school and brought her home for the day, allowing her to avoid the schoolwork she'd found difficult and frustrating. Following implementation of the plan, such episodes were no longer "rewarded" in this way. Instead, Sam was escorted to her relaxation room and allowed to calm down without receiving a great deal of adult attention. And if Sam's parents had to be called to school, they did not bring her home; instead, they stayed only long enough to help her calm down and follow directions to return to class.

The vision grows

Sam's school behavior changed dramatically over a six-month period. Old habits sometimes resurfaced, however; so school personnel and Samantha's parents monitored her progress daily, adjusting the plan as necessary. Sam's parents and teachers sent a notebook back and forth every day. In the notebook, school staff detailed any behavioral events that had occurred that day. In return, Sam's parents reported any mood changes, bad nights or behavioral events that had occurred at home and might serve as "setting events" for problems in school the next day. School staff responded to these events with extra

The Fake family: (from left) Ken, Samantha and Susan.

Get Going!



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vigilance that helped them stop problem behaviors before they started. The notebook was also a means for sharing scheduling changes at school or at home that might confuse Sam. Sam herself was responsible for making sure her parents saw her daily self-management checklist.

The same behavioral support strategies were used in all Sam's environments. All the adults involved with Sam—including her therapists, school choir director, physical education teacher and bus driver—learned how to use positive behavioral support procedures, how to recognize the triggers that signaled a potential behavioral outburst and the procedures to use if inappropriate behaviors occurred.

As Samantha's new life took form, changes happened at home and in the community, too. Sam's "action group" evolved to include new teachers, therapists, peers and other significant people in Sam's life, and the group's vision for Sam grew beyond improving her classroom behavior. Together, the team began to envision Sam having a lifestyle that included peer friendships and recreational opportunities in the community.

Now, two years later, much of that dream has become a reality. Sam not only continues to do well in school—making the honor roll every semester of her sixth-grade year, for example—but she has also become involved in her community. She participates in the Special Olympics and is active in her church. She's taken swimming lessons and attended day camp. And, perhaps most importantly, she has friends with whom she can share these and other activities.

"We were able to put her right in the community by setting goals for her, by asking friends, relatives and professionals to share their vision and especially, by asking Samantha what she envisioned for herself," says Susan Fake. "Our lifestyle planning team just kept on growing... We now meet once every six months to touch base on Samantha's progress, plan new activities and set new goals. I believe this planning process should accompany the positive behavior process when the child's behavior is under control and the child is making good choices." **EP**

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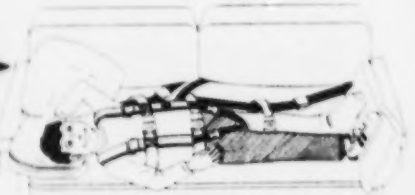

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Fathers' Voices

Both Sides of the Coin

A school principal parents a son with Angelman syndrome

by Dennis Tetreau

Thirteen years ago, Kyle was born with all the pomp and pageantry of a first son and second child. A few months later, my wife and I realized something was wrong.

Just after Kyle's second birthday, doctors diagnosed him with severe developmental delay and a seizure disorder. It wasn't until just before his ninth birthday that he was diagnosed with Angelman syndrome, a rare genetic disorder characterized by profound developmental delays, neurological problems, lack of speech and stilted gait.

Although I had been an elementary school teacher and principal for many years, I didn't have any experience working with children with disabilities. I had no clue as to what my family's future held.

Changing hats

My thinking moved to a new place with my son's birth, our subsequent encounters (sometimes battles) with physicians and specialists and our frustrations about not knowing how to help Kyle. Our family learned to deal with the looks and comments of strangers and shared surprising moments of joy over Kyle's loving personality and slapstick sense of humor.

Kyle, 10, gets a lift from Dad as they hike in Yellowstone Park.

But when it came time to navigate Kyle's education, even I found the system perplexing. The school didn't always understand my priorities and concerns as a parent. As a principal, I tried to draw upon my parental experiences to help my staff understand what other parents were going through. I changed hats so often—principal, parent, principal, parent—that I felt as if I were two different people. In reflecting on my conflicting roles, I discovered how intensely I felt about inclusive education.

I believe every child has the right to the best education possible and that this can and does occur when children with special needs are integrated with their peers. In inclusive settings, the child with special needs has role models for appropriate behavior and is part of a group of active, learning, playing children. Children without disabilities learn to accept differences in appearance and capabilities.

I first saw this when my daughter, Jennifer, was in an elementary classroom with Kelly, a girl who had cerebral palsy. The children in the class accepted Kelly and included her in their activities. Jennifer talked about her a lot—not as the girl in the wheelchair, but as a friend. I thought perhaps Jennifer's attitude had much to do with being Kyle's sister, but I later found out most of her classmates felt the same way.

Facing a stark reality

When Jennifer started school, I was tremendously excited, proud and a little anxious. I knew she would have lots of friends, fit in with all the other children and learn everything the teachers could teach her.

But when Kyle started school, it was different. I had to face the stark reality that my son was not "typical." I was forced to imagine what other people saw when they looked at Kyle. He was no longer just our cute little blue-eyed boy with blonde curls and a ready smile. At age five, he was three to four years behind his classmates in social, intellectual and motor-skill development. He had no real communication skills except pinching and pulling hair when he was angry or frustrated and laughing and bouncing when he was happy.

I wondered whether Kyle would fit in, make friends or even be able to participate in daily academic activities. I was overwhelmed with a rush of old feelings: Why me? It's not fair! What can Kyle do? Does he even belong in this "normal" world?

From fear to hope

Eventually, my attitude about Kyle and his education changed from fear to hope, but it didn't happen overnight.

First, we began to notice Kyle's social progress. We discovered that other children sought him out as a playmate. My wife and I learned from his classmates' parents that Kyle was an everyday topic of conversation at their dinner tables. I slowly realized that the other children had become

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These are descriptions of Children's Extended Care Center (CECC), which provides comprehensive health care, therapy and education in a residential setting for children with complex medical and developmental needs.

But it's the little things that make all the difference.

"The staff show such devotion to the kids," says a parent whose 11-year-old son is a resident at CECC. "I don't know how they do it. Even little things never get overlooked, like keeping chapstick on hand for Matt's lips."

All staff members at CECC—from nurses to teachers to administrators to groundskeepers—extend extraordinary care to children everyday, in countless small ways. They know who enjoys hustle and bustle, who prefers peace and quiet. They remember to open a window to let in a spring breeze, or to choose flowers both for appearance and fragrance. Every wheelchair has a handwritten card on the back, alerting staff to that resident's likes and dislikes.

Located in Groton, Mass., CECC admits and offers short-term and long-term

care to children from birth to age 22. All services are tailored to the needs of each child and family. In addition to receiving skilled nursing care, children participate in a school program, where an integrated curriculum matches activities with abilities.

Through the "Into the Community" program, CECC residents mix with the neighboring community and members of the community join activities at CECC. Several CECC residents attend nearby public schools for a few hours a week accompanied by a CECC staff member.

A subsidiary of Children's Medical Center, CECC is housed in a cheerful, two-story building in a residential neighborhood. The grounds include a large outdoor play area, gardens, and a swimming pool, allowing residents and visitors to enjoy a variety of outdoor activities.

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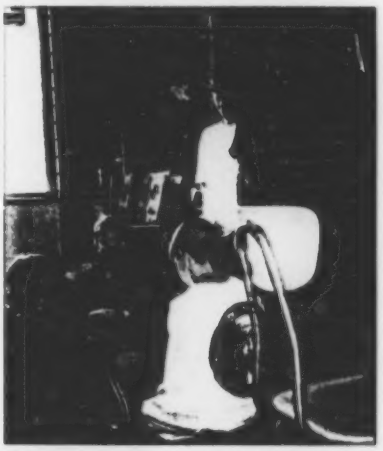
increasingly accepting of his (and other children's) differences.

My change in attitude continued with the assistance of Kyle's teachers. They helped us see that he was making friends and mastering skills like sorting and matching. We began to see how Kyle's presence contributed in positive ways to the school, and my fears began to subside.

Finally, I had to realize that my expectations for Kyle were too low. I had focused almost exclusively on wanting Kyle to fit in and be accepted. Academic skills had barely entered my mind. I remember being elated at one meeting with Kyle's teachers,



Kyle, 12, hangs out with his friends in their sixth-grade classroom.

because it was the first time I saw people expecting something of Kyle beyond "fitting in." Before he entered school, no one had ever asked us what we thought of his potential or what we hoped he would achieve. We were told only that he had profound disabilities and would probably never walk, talk, feed himself or use the toilet independently. Kyle's teachers helped me focus on the things Kyle *could* do, and I was able to adopt a hopeful attitude about his education.

The magic of positive feedback

Today, as I watch my school staff work with discouraged or indifferent parents, I continue to see the magic

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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positive feedback can bring. Educators can provide positive feedback in many ways. At my school, we send children home with a daily journal describing their interactions with other children. We also send lots of schoolwork home with the usual stickers and happy faces. We call parents with encouraging news.

My personal experience helped me learn how important that kind of feedback can be. In Kyle's case, it was his teacher emphasizing his successes that made me understand he did belong in a regular school and that he would have friends and accomplish some academic goals. When Kyle's teachers informed me of his progress, I found myself moving from a sense of anguish to an unexpected feeling of joy.

The staff at my school also helps parents see their children's progress by videotaping the children in different activities. Parents may not know that their child has made a stride, but they can surely see it on videotape. Kyle's teachers videotaped him three or four times in kindergarten. It was so easy to see his growth that I have asked his subsequent teachers to do the same.

Optimistic outlook

Kyle, now 13, is in seventh grade. His hair is a little darker and the curls are gone, but he still has those bright blue eyes and a ready smile. He has grown so much in his physical capabilities. He walks independently, though balance is still a problem. He can hold a pencil and scribble some pretty attractive "art," his toilet training is progressing well and he no longer needs help walking down the stairs.

Socially, Kyle has made incredible progress. He has school friends who come over to play, he has been invited to schoolmates' birthday parties, and he attends an integrated swim and gym class.

Despite his father's fears, six-year-old Kyle had a successful first year of school, making friends and mastering some academic skills in kindergarten.

Kyle now communicates using

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Fathers' Voices

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photographs, choosing what he wants from a selection of more than 100 photos. Kyle has no speech, but his receptive vocabulary is at the three- to four-year-old level. He has maintained his wonderful personality and his uproarious sense of humor.

Now, in the intermediate grades, the difference between Kyle and his classmates is widening. I know there are difficult times ahead, but I also know I will be able to deal with them. It helps to look at the old videos of Kyle and see how far he has come. When I do, I realize how great a role his teachers and classmates have played in his growth. I am grateful to the teachers who helped me see my son's potential and who gave me the chance to be a contributing partner in his education.

I've learned that because of their dealings with some professionals, parents of children with disabilities are often painfully aware of their children's limitations. Many feel helpless and discouraged. They may avoid becoming involved with their child's education because they fear that the teachers will focus only on their child's disabilities. But I've also learned that when educators make the effort to help parents become more involved, parents set higher and more significant goals for their child's education. And everyone experiences the joy of success. **EP**

Dennis Tetreau is the principal of the A.S. Matheson Elementary School in Kelowna, British Columbia, Canada. He lives in Kelowna with his wife, Teresa, daughter, Jennifer, 15, and son, Kyle, 13. In August 1996, Dennis was a speaker at the Canadian Angelman Syndrome Society conference in Calgary, Alberta. The very active Tetreau family enjoys traveling, playing volleyball, reading and exercising together.

A longer version of this article appeared in THE SCHOOL ADMINISTRATOR *(November 1995). It has been adapted with permission.*

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EDUCATION

Dispelling the Myths
ABOUT SPECIAL EDUCATION
A message for parents

by Judith E. Heumann

As parents, each of you—more than anyone else—feels a sense of responsibility for and dedication to ensuring that your children receive the education to which they are entitled. I have met with hundreds of you over the past few years, and I know this to be true. As Assistant Secretary for the Office of Special Education and Rehabilitative Services (OSERS), I share that sense of responsibility, as we work together in partnership to achieve positive outcomes in the delivery of special education services.

To help us fulfill this dedication and carry out this responsibility, it can be helpful, from time to time, to review our successes in order to strengthen our resolve and enhance our vision for the future. To me, this is an exciting endeavor, because we know full well what the Individuals with Disabilities Education Act (IDEA) has done and is doing for students with disabilities throughout the country.

It's probably safe to say that few laws have generated as much controversy over the past 20 years as the IDEA. This law, which has done so much for so many, has been the subject of much misunderstanding. Indeed, the recent negative attention special education has received in the national television and print media has underscored the misinformation often characterizing public discussion of the IDEA's past. I firmly believe that healthy and constructive criticism can be a fundamental force for improvement; however, much of the recent criticisms of the IDEA, in my opinion, are based to a large degree on myth, fear and shortsightedness.

Through this article, I hope to dispel some of the more prevalent myths that, like shards of glass in a wind storm, have the potential for doing damage to the underpinnings of the IDEA and the basic principles it protects. The more we know about the IDEA and about the capabilities of children and youth with disabilities, the easier it will be for all of us to share this truth as we meet with other parents, school officials and administrators, and as we work to effect change at the local, state and federal levels.

Dispelling myths

We have much data about the effectiveness of the IDEA and the great strides made by children and youth with disabilities. Moreover, we are working hard to increase the data available to us. One important step is ensuring that students with disabilities are included in state- and district-wide assessments and that the results are properly reported. This will help us identify successful practices that lead to improved results for students with disabilities. Another important step is conducting major studies—like the recent National Longitudinal Transition Study—that tell us much more about what helps students with disabilities succeed in school and in later education and employment. For example, we learned from this study that vocational instruction reduces course failure and assists in dropout prevention. Moreover, participation in work experience programs has a sizable positive impact on student performance. With this new information, families and schools can make more informed decisions about the appropriateness and availability of vocational education for students with disabilities.

Chicot Elementary School • Little Rock, Arkansas

Children with disabilities at Chicot Elementary School enjoy the friendship and support of Circles of Friends throughout their school years.

In 1993, the Arkansas Governor's Developmental Disabilities Council awarded a $27,300 renewable grant to Chicot Elementary School to help them develop an inclusive education program. The school used these funds to train its entire staff to meet the needs of all students, including those with disabilities.

Chicot also created a team of parents, school staff, administrators, representatives from the Department of Education, and local college and university staff members. The group, named CORE (Collaborative Objectives Through Regular Education), was dedicated to expanding inclusion at Chicot Elementary.

1996 EDUCATION AWARD

CORE founded a support group for children who use augmentative communication devices and worked with Chicot teachers to implement a Circle of Friends program in which students with disabilities are supported by other students. The same students remain in a child's Circle of Friends from grade to grade, providing continuing encouragement and friendship. They also meet with the child, the child's parents and school staff to discuss how to meet the child's needs. These Circles of Friends help students with disabilities become fully included members of the Chicot student population.

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Judith E. Heumann, Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education, meets a young student at the TRIPOD Preschool in Burbank, California. TRIPOD is an educational program serving children who are deaf or hard of hearing.

Despite the available information, we still find that a number of pervasive myths surround the provision of special education services to children and youth with disabilities. I will address a few of these myths by providing the "reality check," as I see it, that each myth deserves.

• **Myth:** *Special education is costing too much, because there are no demonstrable positive results.*
• **Reality:** The IDEA has played an important role in improving the lives of people with disabilities, as noted in a recent respected poll: "In one key area, there are hopeful signs. Largely due to the [Individuals with Disabilities Education Act] of 1975, the gap in education is beginning to close." (Harris Poll, National Organization on Disability, 1994, pp. 3–4.)

Over the past 20 years, the IDEA has brought about an increase in successful educational results for students with disabilities. From the 1984–85 school year to the 1991–92 school year, the percentage of students 16 years of age and older exiting the educational system with a diploma or a certificate of completion has gradually increased from 55 to 64 percent.

Because of the increased successful educational results achieved through the IDEA, recent graduates are more likely to be working than people with disabilities of working age as a whole. In 1990, the percentage of young adults with disabilities who were working was nearly double that for all working-age people with disabilities—62 percent versus approximately 32 percent.

Of course, many students do not go on to work directly after leaving high school; instead, they enroll in college. Here, too, students with disabilities are making great strides. The percentage of freshman reporting disabilities has more than tripled, from 2.6 percent in 1978 to 8.8 percent in 1991.

The percentage of students with disabilities served both in regular schools and in regular classes within those schools has continually increased. In the 1984–85 school year, only one-quarter of these students were served in regular classrooms for at least 80 percent of the school day. By 1992–93, that percentage had increased to 40 percent.

The decline in institutionalization for children with mental retardation and/or developmental disabilities also has been dramatic. The number of residents in all residential facilities, including state and community institutions, has declined by almost half, from 90,942 to 45,747 children. The decline for those residing in state institutions is even greater. The number residing in such facilities in 1991 was less than 10 percent of what it was in 1965; in fact, the number today is slightly lower than in 1910, when the overall population of children was much smaller (10,547 in 1910 versus 6,944 in 1991).

Today, infants and toddlers with disabilities receive early intervention services under Part H of the IDEA—services that help get them on the right developmental track from the beginning. Children with disabilities go to preschool and school in their communities with their brothers and sisters, play on Little League teams and sing in church choirs. And when they finish school, they go to work and pay taxes, enjoying the opportunities of this great country, while accepting the responsibilities of citizenship.

• **Myth:** *All children with disabilities require extremely expensive personnel, transportation and other services to allow them to receive an appropriate education.*

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West Chicago Elementary School • District #33

West Chicago, Illinois

West Chicago Elementary School District students help one another in and out of the classroom. Here, fifth graders at Indian Knoll School enjoy a game of four-square.

In 1990, West Chicago Elementary District #33 began including students with disabilities—one of the first districts in the state to do so. That year, five students were included. Now, District #33 schools offer fully inclusive educational programs to more than 160 students with disabilities who attend regular classrooms with their peers.

West Chicago elementary schools strive to meet two goals through inclusion. First, they work to build each student's skills. Second, they aim to create an environment in which all students can develop relationships and friendships. These goals are accomplished by encouraging students to support each other and by hiring staff to help meet the needs of both students and teachers. This staff includes 15 facilitating teachers certified in special education and 96 teaching assistants. Substitute teachers are provided so all staff members can attend IEP meetings and weekly meetings at which IEPs are discussed.

1996 EDUCATION AWARD

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Morristown Elementary School • Morristown, Vermont

At Morristown Elementary School, there are only four rules: Be kind, be respectful, be safe and try your best.

Each morning at Morristown Elementary School, teachers and students sit in a circle to greet each other, play an activity and share their thoughts and feelings. These "Morning Meetings" foster a healthy school climate—a key element in Morristown's strategy for meeting the needs of all children through inclusive education.

School staff view collaboration with parents and the community as extremely important. Parents and community members volunteer in many capacities, including as members of the site management team that works with each student who has special needs. Teams consist of teachers, support personnel and parents.

Morristown is determined to "walk the talk," supporting teachers as they take risks and learn new teaching methods. Teachers are given the chance to learn from both successes and failures. Consequently, the faculty and staff are continually looking for and experimenting with new and better ways of teaching and learning. Appropriately, the school's motto is "Community of Learners with the Courage to Grow."

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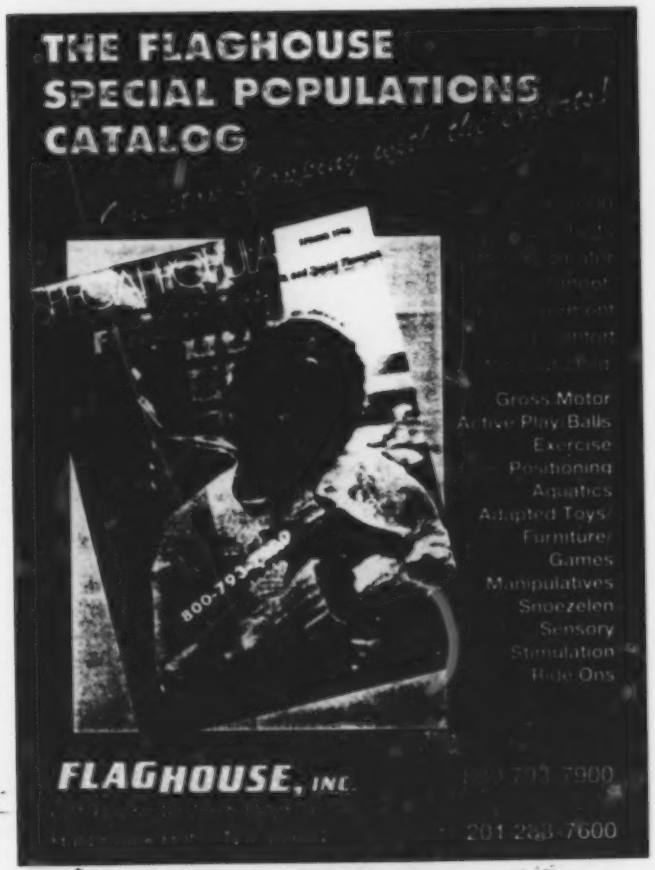
• **Reality:** Of those children and youth receiving special education and related services in our nation's school systems, only a tiny fraction incur significant expense in the kinds of services they require. The vast majority of students with disabilities never incur the significant expenses touted as standard for all children with disabilities.

• **Myth:** *No student with a disability can be suspended or expelled for more than 10 school days.*

• **Reality:** A student with a disability *can* be suspended or expelled for more than 10 school days, if it is determined that the misconduct is *not* a manifestation of the child's disability (subject to parents' right to due process on the correctness of that determination) and provided that the same policy is applied to students without disabilities. During long-term suspension or expulsion, each student to whom the IDEA applies must be offered a program of appropriate educational services. A student who brings a gun to school can be moved to an alternative education program for up to 45 calendar days or longer if a due process proceeding is initiated—regardless of whether the behavior is a manifestation of the disability.

• **Myth:** *Even if a student with a disability brings a firearm to school, he or she cannot be removed from the classroom.*



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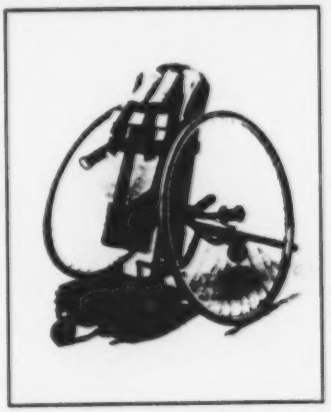

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• **Reality:** If a student with a disability brings a firearm to school, the public agency may immediately place the student in an alternative setting selected by the Individualized Education Program (IEP) team for up to 45 days. If the parents initiate a due process proceeding, the student remains in the alternative setting until the matter is resolved.

• **Myth:** *Children with disabilities in the regular classroom are a detriment to students without disabilities because they are disruptive and take time away from teaching and learning.*
• **Reality:** We are finding that with the right supports, the presence of children with disabilities in the regular classroom often has a positive impact on students without disabilities. These students learn to understand and help people who are different from themselves and who may need special equipment and services to help them learn. Rather than being frightening or disruptive, the presence of students with disabilities provides invaluable lessons for all students, teaching values of compassion and caring and promoting growth in social awareness and empathy.

One education system

Of course, regardless of these myths, there is still much room for improvement in the education of children with disabilities in this nation. Too often, special education is seen as a separate system and a separate place. Instead, we must promote education reform from a perspective that says we have one education system that is responsible for assuring that *all* its children perform more effectively, learn to higher standards and show meaningful progress.

Too often, special education is held responsible for "fixing" children. However, we know that the education system must focus more on *preventing* problems from occurring in the first place. For example, everyone concerned with the education of the 50 million students in our nation's schools should take greater responsibility for assuring better preparation of all teachers, including training teachers to teach reading more effectively. Many children who end up receiving special education services because of the presence of a learning disability, could and should have had aggressive reading intervention by well-trained professionals when they first started learning to read. When such early intervention occurs, fewer students need special education services.

Yet, despite these challenges, we know that the IDEA has helped millions of youngsters with disabilities become educated, productive citizens. By focusing attention on this important truth, we can continue to move forward in improving educational outcomes for *all* students. It's up to all of us to play a pivotal role in this process, whenever and wherever we can. **EP**

Judith E. Heumann is Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS) of the U.S. Department of Education.

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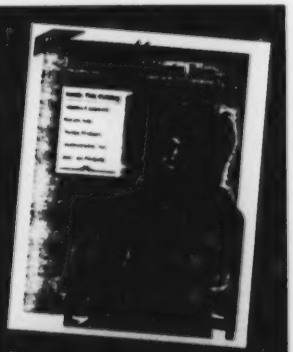

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What Controversy Over Educational Methods?

For us, there's only what works for Emily

by David W. Hewlings

Our brand-new baby girl was only nine weeks old when we learned of her hearing loss. Emily did not respond at all to the brainstem test. Although we still didn't know the exact numbers, we knew her hearing loss was profound. And, because we learned of Emily's disability very early, we knew we had been given the valuable gift of time.

So we set out to learn about educational options. Like other parents new to the deaf world, we were overwhelmed by the number of approaches: oral, auditory-verbal, total communication, signed English, American Sign Language, cued speech. And then there were the technological solutions: hearing aids, FM systems, frequency transposition systems, cochlear implants, bone conduction devices. So many choices! Had someone proposed teaching Emily to communicate by banging coconuts together, we wouldn't have blinked.

Not surprisingly, such an abundance of solutions generates a fair amount of disagreement among proponents and professionals. But we're willing to try anything that might allow Emily to bridge the communication gap and function independently out there in the big world. That is, after all, our job. So we're grateful for the number of options, because we can choose what's appropriate for Emily. And we've come to believe that the arguments over which is the "best method" simply miss the point.

No second chances

Controversies begin when professionals market their educational approaches to parents. They do so by pointing out the benefits of one method over others. In teaching children who are deaf, sign language proponents assert that the building blocks of language are the same no matter what form the symbols take. They claim that sign language is a more natural language for children who are deaf, implying that teaching them instead to hear and speak is somehow unnatural. At the other extreme, auditory-verbal practitioners point out that almost every child has some level of residual hearing, and that it can be nurtured to allow hearing and speaking skills to emerge. They imply that parents who don't at least try their approach compromise their children's progress right from the start.

Three-year-old Emily Hewlings received a cochlear implant in July 1995, and now attends the Listening Center at Johns Hopkins in Baltimore, Maryland. "We're happy to be working with clinicians who believe in combining approaches to meet the child's needs," says Emily's father, David.

Professionals live in a different world than do parents. Professionals deal with hundreds of children, measure success through statistics and tweak their approaches only after careful experience and study. But parents don't have second chances. We deal with only one statistic—one out of one. We have to make the right decisions one child at a time.

When Emily's FM system didn't give her enough access to sound, we considered a cochlear implant. If the auditory-verbal approach doesn't work for her, we'll try something more visual, like cued speech or sign language. After all that, if she still can't communicate, maybe we'll get out the coconuts. For us, there is no method that works for most children. There is only what works for Emily.

No need for controversy

As Emily's parents, we are responsible for making sure that she gets what she needs. It is not only our right, but our duty to make those choices for her. Why then do only a few professionals support parental choice by offering more than one approach, or even a combination of approaches, to teaching children who are deaf? When a child's needs change or new needs emerge, why do parents have to change horses in midstream? If professionals would simply focus on meeting an individual child's needs using all available tools, the arguments would cease.

There is no controversy in this house. There is only love, resolve and incredible faith and trust in Emily's abilities. As parents, our job is to work ourselves out of a job. And we know that as long as we do the job right, nothing will stop our Emily. **EP**

David Hewlings lives in Chester County, Pennsylvania, with his wife, Linda, and daughters, Emily, 3, and Leah, almost 2. An earlier version of this article appeared in THE LISTENING POST *(Spring 1995, "What Controversy?"), published by the Helen Beebe Speech and Hearing Center in Easton, Pennsylvania.*

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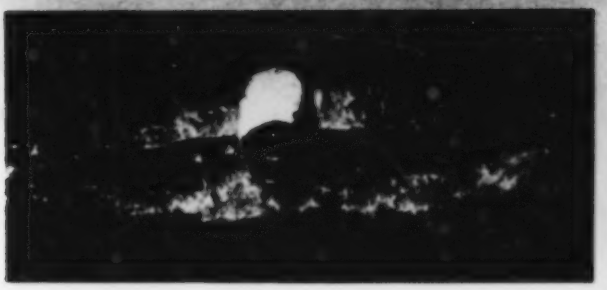

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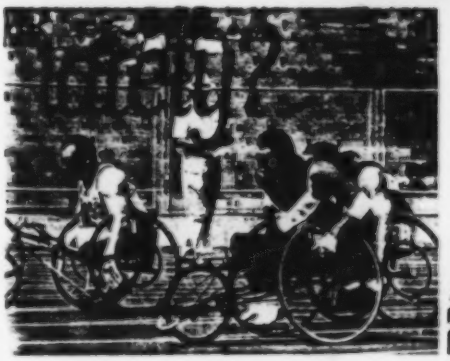

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EDUCATION

When Parents Choose Private Education

PART ONE: Tuition Reimbursement and Special Education Services

by Barbara J. Ebenstein

The Individuals with Disabilities Education Act (IDEA), guarantees children with disabilities a "free, appropriate, public education" in the "least restrictive environment" (LRE). The law prefers that children with disabilities be taught in regular classrooms in their local school. When this is not possible, the school district places the child in a self-contained special education class in a regular school with as much mainstream activity as possible. When the school district cannot provide an appropriate education within the district, it must send the child elsewhere and pay for the child's tuition and transportation. This can be a special class in a nearby school district, a cooperative education services program, a special public school or a special private school. Federal regulations require that special private schools meet certain state standards before school districts may enroll children in them. Some states, such as New York, maintain a list of approved private schools; other states, such as South Carolina, approve schools on a case-by-case basis. School districts cannot place a child in an unapproved school or an out-of-state school without permission from their state's department of education.

A decision in a 1985 Supreme Court case, *Burlington School Committee v. Department of Education*, gave parents the right to receive reimbursement for private school tuition from the school district when the district fails to provide an appropriate education under the IDEA and the parents obtain appropriate services at a private school.

The 1993 Supreme Court case *Florence County School District Four v. Carter* clarified that right with regard to the issue of private school approval. In this case, the parents of Shannon Carter, a ninth-grader with a learning disability, disputed the IEP (individualized education program) proposed by their school district because they believed the services offered were not sufficient to meet Shannon's needs. Rather than accepting the IEP, Shannon's parents enrolled her in Trident Academy, a private school for children with disabilities that had not been approved by the state. The United States Supreme Court ruled that state approval of a private school is necessary only when a school district places a child. But when the school district fails to furnish an appropriate education, parents may seek reimbursement for funds spent on tuition at a private special education school even if the school is not state-approved.

The Hill Center • Durham, North Carolina

Elementary school reading buddies take turns reading aloud to each other.

The Hill Center, a co-educational day school for students with learning disabilities and attention deficit disorder, was founded in 1977. The school offers an intensive academic program to 125 students from kindergarten through 12th grades. The Hill Center serves students from 65 public and private schools in seven North Carolina counties.

Students attend classes at the Hill Center for one-half of the school day and spend the remainder of the day in their local public school or a private school in which they are enrolled. This schedule gives students the benefits of an intensive remediation program, while preserving normal social interactions at their home school.

The Hill Center also offers several outreach programs to surrounding communities: the Hill Summer Program, Tutoring Connection, study skills courses, educational evaluations and teacher training workshops. A planned new facility will enable the Hill Center to increase student enrollment by 30 percent, develop a national teacher training center, incorporate new technological advances into the curriculum and expand their already rapidly growing base of outreach services.

1996 EDUCATION AWARD

Exercise caution!

An important caution: These cases only give parents the right to sue school districts for reimbursement of tuition already expended. There is no guarantee that parents will win these cases, and that a court will force the school district to reimburse the money parents have spent. It is not like a voucher system; parents should not believe that they need simply select a private school, enroll the child, pay the tuition, and then request reimbursement.

School districts have been required to reimburse private school tuition *only* when they have been unable to provide a free, appropriate, public education either because the child's disability is such that no appropriate placement can be found by the district or because the district has made gross procedural errors—such as failure to

About This Series:
Private schools attract children with disabilities because they offer small classes, a varied curriculum and a sense of community. Some private schools offer intensive programs taught by teachers who share a common philosophy and training. Some parents find that private religious schools are more accepting of diversity among children. Other parents prefer to teach their children with disabilities at home.

Still unsettled is the obligation of public school districts to children with disabilities who attend private schools or who are educated at home. Are children attending private schools eligible to receive special education services at public expense? When must a school district pay private school tuition for a child with a disability? Can parents educate their children at home and still receive some special education services from their school districts? Several important cases dealing with some of these important questions are currently in the federal appellate courts. The courts' answers may hold tremendous benefits for children and equally consequential financial liability for school districts.

This article deals with the question of when a school district is required to reimburse tuition for children with disabilities attending private schools. It also looks at the obligation of school districts to provide special education services to children attending private schools. The second article in this series will examine the question of publicly funded special education services for children attending religious schools or being educated at home.

evaluate a referred child or failure to develop an IEP—that have had the result of denying the child a free, appropriate public education. And sometimes, even in these cases, the court does not order tuition reimbursement, but merely requires the school district to develop an appropriate IEP. Furthermore, because federal law prefers that children with disabilities be educated in the "least restrictive environment," the courts may not order a school district to reimburse special private school tuition for a child who could have been educated in a regular school.

Parents must recognize the financial risk involved in these cases. Even when parents win, reimbursement is limited to an amount the court considers "reasonable costs" of a private school. This means that parents may not be reimbursed for the full cost of tuition expended, or for their full legal fees.

Special education services

Some parents choose to place their children with disabilities in private schools and pay the tuition themselves. Under the IDEA and other federal laws and regulations, the school district still has some obligation to these "unilaterally placed" children. First, school districts are required to identify, locate and evaluate all children with disabilities who reside within the district. Second, school districts must keep track of children who are eligible for special education services but attend private schools, meaning the district must know what school the child attends. Finally, school districts must provide all children in the district who have been identified as having disabilities with IEPs offering publicly funded placements with appropriate goals, objectives and related services.

Many parents who reject the offered IEP placement and choose to pay private school tuition still want the school district to provide special education services such as therapies and consultant teachers. Federal regulations require that the services provided to children with disabilities placed in private schools by their parents must be "comparable in quality, scope and opportunity for participation" to services provided to public school children. Unfortunately, the U.S. Office of Special Education Programs (OSEP) has interpreted that to mean that school districts should spend a comparable amount of federal money on privately and publicly placed children. The discrepancy between the wording of the regulation and its OSEP interpretation has led to varying court interpretations of the rights of families and the obligations of school districts.

Following the OSEP interpretation, a school district would determine the number of children within the district who have disabilities, and then calculate the percentage that attend private schools. For example, if the school district has 500 children with disabilities and 50 are in private schools, that is 10 percent attending private schools. OSEP's formula would require the school district to allocate 10 percent of the district's IDEA funds to serve these 50 children.

The problem is that the federal government provides very little special education funding. So if that district

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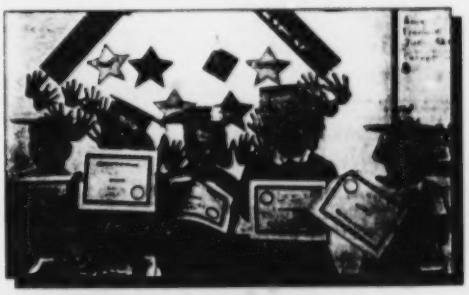
Metro Deaf School • St. Paul, Minnesota



(Left to right) Tommy Mulally, Bobby Siebert, Trent Lukin, Jerica Poehlmann and Shannon Boelter receive their diplomas at kindergarten graduation.

Metro Deaf School (MDS) is a four-year-old charter school—a public school approved by the State Board of Education, functioning under a charter granted by a local school board and designed by parents and teachers. In the past, children with hearing impairments in the Minneapolis-St. Paul area had the options of inclusion with hearing students or attendance at the state residential school for the deaf. Community members felt there was a great need for a school that would allow these children to live at home while receiving a quality education with deaf peers. Minnesota's Charter School Law, passed in 1991, provided a means to achieve this dream.

The 40 students at MDS study a typical elementary school curriculum with one important difference—American Sign Language (ASL) is the instructional language. English is taught as a second language; individual and small-group instruction in spoken English is available. The school also emphasizes participation in the deaf culture and community.

MDS is becoming recognized as a national model program, one of only a few applying a bilingual-bicultural philosophy to the education of deaf children.

1996 EDUCATION AWARD

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Richland County • School District One

Columbia, South Carolina

Kim Bennett (left), regular education teacher, and Robbin Taylor (right), resource teacher, began co-teaching at John P. Thomas Elementary School in 1995.

Richland County School District One is one of the first districts in South Carolina to provide formal training and ongoing support for co-teaching, a practice in which regular- and special-education teachers share responsibility for planning, delivering and evaluating instruction for all students. Co-teachers work as a team and capitalize on each other's talents.

Co-teaching allows students with disabilities to be included in regular classrooms. Jean Haddock, special education teacher, says, "For some time now, students with hearing impairments have been successfully included at our school. Jane Ward [regular education teacher] and I are eager for our students to experience this same success." Dr. Donald J. Henderson, District superintendent, says, "Co-teaching promotes a collegiate relationship between regular and special education teachers. This professional interaction encourages all students to work together to develop knowledge and skills necessary for success."

1996 EDUCATION AWARD

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receives $9,000 of federal IDEA funds a year, OSEP requires them to spend just 10 percent of $9,000—or just $900—on services for those 50 children with disabilities in private schools. Obviously, this would not be enough money to provide anything more than a few therapy sessions for one or two children.

Federal regulations require that the school district consult with private school representatives to decide how to allocate these meager funds. As long as the school district has a rationale for its allocation of funds, it may choose to serve only children with a specific disability or to provide only one or two limited services. For example, a school district may decide to send a speech therapist once a month to provide services to two children from the district who attend the same private school.

The OSEP formula represents a school district's minimum requirement under federal law. Some school districts

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voluntarily use state or local funds to supplement federal IDEA funds, and provide additional services to private school children with disabilities. Some small school districts that would receive little federal IDEA funding anyway decide to turn down this funding completely, which releases them from *any* obligation to provide services to students attending private schools. Parents need to know the policy of their school district.

Due process rights

A 1996 Mississippi case, *Natchez-Adams School District v. Searing*, involved a seven-year-old boy with cerebral palsy whose parents enrolled him in a private school. At that point, the school district automatically stopped providing him with services, and failed to develop a new IEP. Applying the OSEP formula, the court determined that the district's automatic discontinuation of services violated IDEA procedure, because the district could provide no rationale for their allocation of federal funds to children with disabilities attending private schools. The court also declared that the boy's old IEP, which specified the provision of occupational therapy, was still valid, and they ordered the district to continue providing that service. The court stated that if the district developed a new IEP that did not include occupational therapy, the parents could exercise their due process rights again.

OSEP has stated that there is no individual entitlement to special education services at private schools. That means that no particular child has a right to services. But, as the *Natchez-Adams* case illustrates, courts have decided that parents may exercise their due process rights if they are dissatisfied with the procedure used by a school district to deny services to children attending private schools. This means that parents have the right to an impartial hearing, an appeal to a state review office and a further appeal to the federal courts. **EP**

Barbara J. Ebenstein is a partner in the law offices of Ebenstein & Ebenstein in New York City. She lives with her husband, Dr. John E. Handelsman, and their three daughters, Sarah, 15, Leanne, 13, and Risa, 10, who has a disability.

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- Harbison West Elementary School, Columbia, South Carolina
- Meridian Community Unit School District #101, Mounds, Illinois
- Pine View High School, St. George, Utah
- William Thomas Middle School, American Falls, Idaho
- Winfield School District #34, Winfield, Illinois

PHOTO BY STEVE HEASLIP

(Left) Kathleen Lehane helps Abbie Bowden with a writing lesson in their third grade classroom at Cotuit Elementary School in Barnstable, Massachusetts. Barnstable School District has established "mentor" relationships with neighboring school districts that are just beginning to implement inclusive educational practices.

(Righjt) At Winfield Middle School in Winfield, Illinois, Tim Herzberger (front) and best friend Nathan Williams celebrate the last day of classes. Winfield School District #34 has been including students with severe disabilities since 1991.

(Left) Students conduct a science experiment at Harbison West Elementary School in Columbia, South Carolina.

(Right) Jennifer Wagner, 6, shows off her painted face at Enosburg Elementary's Vision Celebration in March 1996. This rural school in Enosburg, Vermont, became fully inclusive in 1993.

EDUCATION

"My mom and I thought we were ready for everything before I started my first year of college," writes Abby Albrecht, 20. "Little did we know how much we still had to learn."

School Daze

What I wish I had known before I started college

by Abby Albrecht

My mom and I thought we were ready for everything before I started my first year of college. We had visited the campus, met with the Office for Students with Disabilities and enrolled in classes. Little did we know how much we still had to learn.

Everything about college, from the usual task of finding classrooms to the unusual routine of hiring aides, is a little more difficult when a student has a disability. This doesn't mean school can't be fun. It just means thinking ahead.

Personal care assistants

It's hard to move away from home the first time. It's even harder when you have to count on strangers to take care of you. Most schools do not provide personal care assistants for students with disabilities, and the ones that do may provide such services only for freshmen.

Compatibility is one of the biggest considerations when hiring an aide. It's usually best to choose a person with the same general attitudes and values as your family. College is a great place to learn about different cultures and lifestyles. But living in close contact with a person who has greatly different values is more difficult than it might initially seem; little resentments can build up and ruin the working relationship. Diversity is probably best left to a less personal level—like parties.

Patrick Gillespie, a senior at the University of Southern California, learned the hard way how much he depends on his aides. Patrick uses one aide during the afternoon and evening, while his roommate gets him up in the morning and is available in case of emergencies at night. This system worked fine until the night his roommate never made it back to the room.

Patrick's roommate was visiting his parents that evening and couldn't find a ride back until the next afternoon. "It would have been great to have the room to myself," says Patrick, "if I hadn't been stuck in bed." Fortunately, as soon as Patrick's resident advisor was notified about the situation, Patrick's many friends pitched in to get him up and ready to go on with his day.

Perhaps the most important piece of advice regarding aides comes from Patrick—"Make friends quickly, and always have a backup plan." Friends won't necessarily take the job of being an aide, Patrick explains, but there's no substitute for good friends when you need help in a pinch.

Accessibility

Most colleges were built before the advent of laws requiring architectural accessibility. Because of this, classroom accessibility is a gamble every semester. Each school should have an Office for Students with Disabilities, or something similarly named, hidden somewhere within their student affairs or student health departments. This office can help with accommodation—if they are contacted in advance. But don't expect them to drop everything on the first day of classes if you can't get into your science class.

Checking the accessibility of buildings and classrooms even a few days before classes start makes the first day of the semester a lot less stressful. A tour of the campus will also help you gauge the amount of time you'll need to travel from class to class.

But even careful planning won't avoid all surprises. I learned that during my junior year. The only general education classes I had left were those to fulfill my science requirement—not my favorite subject. I chose to take geology as my earth science course because my dad is a mining engineer—it seemed like a big plus since I suspected I might need a tutor—and because I knew the lecture hall was accessible. Then, on the first day of class, the professor announced the location of the lab. Not only would I have to go through two other classrooms to reach it, but because this building didn't have an

839

Although Patrick Gillespie of Shoreline, Washington, is now in his senior year at the University of Southern California, on-campus life still brings occasional new challenges. Patrick's advice to new college students with disabilities? "Make friends quickly, and always have a backup plan." There's no substitute for good friends when you need help in a pinch, he explains.

entrance ramp, I would also have to find a way to use the half-floor lift that was the only way to get in and out of the building. The lift was creepy and noisy, but worse, I couldn't reach the buttons to control it. And the thought of being suspended in midair with only a little metal supporting me and my wheelchair didn't make me feel any better.

My first thought was to have the class moved. Unfortunately, the school's policy is not to move lab classes except for students taking courses in their major fields of study. Two days before the lab started, I was able to talk a friend into getting up early to help me operate the lift. When I needed to leave the building, I stopped to ask for help at the first office I saw. Amazingly enough, it was the Geology Department office and, after that first day, they made sure someone was always waiting to help me before and after the lab.

Health concerns

At college, the last thing you think about is getting sick. Nobody with a full course load has the time to be sick or to spend a week in bed. That's why it is so important to think about health care before an emergency situation arises.

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Circle #840

continued from page 65

Judy Gillespie, Patrick's mom, confesses to being worried about her son's ability to take care of his own health care needs. But, she says, the only thing she could do was trust him. Before he started school, she and Patrick discussed the warning signs of different health problems he might face and how he should react to each. They also checked out the student health center and spoke with his current doctors to get referrals to specialists near the college who would be available if Patrick faced a health emergency with which the on-campus health center was unprepared to cope.

Since a student's medical coverage often changes when he or she moves away from home, the health center is usually the easiest place to go for routine care. It's always a good idea to visit the center before the beginning of your first semester on campus. Introduce yourself to the head nurse and doctor. Make sure the center's staff knows about your disability; if possible, find a specialist who understands exactly what you will need. Your life will be a lot easier if you don't have to explain the details of your disability while trying to get a flu shot or treatment for a lung infection.

Like most other students at his college, Patrick tends to use the student health center almost exclusively. It's the most convenient option, he says. But knowing that Patrick has standing referrals to local specialists gives Judy a little extra peace of mind.

Socialization

Although parents and professors may disagree, college isn't just about studying. College is a place to learn and grow, and often, that growth comes from socializing with other people and learning about different lifestyles.

Monica Lipinski hated high school. She says it felt as if her wheelchair made her invisible to guys and party invitations. Then she started her freshman year at the University of California, Berkeley. Suddenly, she was being invited to clubs and meeting guys who didn't seem to notice her chair.

One night early in her college experience stands out in her mind. Monica's friends had convinced her to go along with them to a local dance club—just to hang out. But since the music was good, Monica started dancing. "Nobody laughed at me," she says. Instead, other people danced with her; one person even thanked her for a dance.

Monica believes that college students generally are more understanding about differences and much more creative in finding ways for everyone to participate in activities. College, Monica discovered, is no place for wallflowers. And that's okay, because Monica is no longer interested in sitting at home alone every night.

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Circle #68

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typical college dorm room or apartment, and you're suddenly dealing with even more interesting obstacles.

Before I began college, my parents and I agreed that an on-campus apartment would be my best choice of residence—affording me both convenience and privacy. Shortly after applying for an apartment, the housing office informed me they had found one that was "perfect" for me… Perfect, that is, as long as the flight of stairs to the bedroom didn't bother me or the aide who would have to carry me up and down it.

After calling the housing office repeatedly in hopes of finding something better, I was ready to give up. Fortunately, my mom wasn't. When we drove to school for new-student orientation, my mom visited the person in charge of on-campus housing while I took campus tours and talked to advisors. By the next day, a first-floor, two-bedroom apartment in the most popular building on campus was awaiting my occupancy.

You probably won't get the perfect room for your needs the first time you fill in a housing application. The best thing to do is to tour the available housing options, choose the one(s) that would work the best, and then keep bugging the housing office until they give you what you want—or the closest possible substitute.

Financial aid

Everyone has heard the line, "…I'm just a poor college student," but it's more than a cliché. College costs are going up, and financial aid never seems to cover it all—especially for students with disabilities. Most colleges compute financial aid awards the same way for all students. They don't seem to consider the extra expenses students with disabilities incur for budget items like aides and specialized personal care items. And, of course, there's always the "nonessentials" to think about—little things like books and food.

My mom filled out my financial aid forms completely—including the "special circumstances" section, in which applicants can explain their need for additional aid. And she made sure to get everything in on time.

But Mom didn't stop there. When I received notice of my financial aid award, she made phone calls and sent another letter requesting still more aid.

Even with extra financial aid due to "special circumstances," financial assistance provided through your school probably won't cover all your costs. Most schools adjust their financial aid packages based on the amount of money your family can contribute and any scholarships you may have earned. Start looking for scholarships early. Not only do scholarships help buy books, food and sometimes televisions, they can also be listed on later scholarship applications as awards received.

In addition to applying for financial aid through the college, my mother also had me contact our state Department of Rehabilitation because they will give academically qualified state residents with disabilities government aid equal to the cost of going to a local state college.

These efforts paid off. I received thousands of dollars in grants and loans from my school, as well as money from the Department of Rehabilitation. I even got some scholarships. Thanks to Mom's persistence, I've been able to attend school—and attend to my schoolwork—without worrying too much about the bills.

Becoming independent

College is a place to explore yourself and your world. At first it may seem like nothing will work out—classes are full, rooms are inaccessible and you don't know anyone who can help. But, it does get better. And after a while, it gets so good that the only reason to go home is to get a home-cooked meal and "borrow" quarters to do the stacks of laundry piling up in your room back at school. **EP**

Abby Albrecht, 20, is a public relations major at the University of Southern California. She also works for her school's student newspaper, THE DAILY TROJAN, and for the Office for Students with Disabilities. Abby's mom, Donna G. Albrecht, is the author of RAISING A CHILD WHO HAS A PHYSICAL DISABILITY (available from Exceptional Parent Library; 800/535-1910; $12.95).

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Reprinted from EXCEPTIONAL PARENT, October 1984

SEX EDUCATION
A Commentary From the Advisory Board

by Betty Pendler

Parents have to recognize that all our children are sexual as well as human. A child's self-image becomes a basic part of his or her sexuality... Much is written about how a healthy personality depends on an early positive self-image—that includes a happy self-awareness of one's body, and pleasurable experiences. That seems to me to be a good way to begin. If your child—through self-discovery and self-stimulation—discovers that his or her body feels good, then it is easy to go on and encourage the youngster later about proper grooming and a good feeling about him or herself.

Self-stimulation

Many professionals in the field of human sexuality write that masturbation is now considered quite appropriate. Masturbation allows a child to get a feeling of self-sufficiency and bodily pleasure... It can contribute to a child's physical and emotional well-being, and does not hurt anyone.

[A] non-judging attitude on our part...would not increase a child's desire to masturbate more often. If anything, it would take away the child's feeling of guilt, and make it easier for us to give the message that it is all right, but that it should be done in private.

Teaching our children

Teaching daughters about menstruation is a subject that haunts most parents. We assume that our daughters with disabilities are not going to understand us. It is very important for both girls and boys to be told in advance about what will be occurring to their bodies. In talking to my daughter, Lisa, I used the idea that these changes would occur because she was *growing up* and stayed away from the words that something will *be happening to her.*

Long before Lisa was ready, I began to talk to her about menstruation. I showed her what she would see when she "growed up." As I was showing Lisa the sanitary napkin, her younger brother, Paul, passed by the bathroom and looked in, so he got a lesson, too. (That was not part of my plan.)

One morning, Paul walked into the kitchen and said to me, "You know the thing you showed us; I think it happened." And Lisa, who has Down syndrome, followed him in and said, "Mommy, I growed up today." It was that easy!

In fact, she was so proud that she began to tell everyone whenever she got her period... Like everything else, I had to tell her over and over again that this was private and that she should only tell me. Eventually, she got that message, too. I tried to explain menstrual pains and told her that sometimes when she eats ice cream, she gets a stomach ache and that it goes away. And after a while, these pains go away, too.

Parents' concerns

It is understandable that parents feel uncomfortable discussing this subject. We are beset with the fear that a basic knowledge of sexual matters will foster experimentation and stimulate sexual behavior. But experts believe that lack of knowledge can be more injurious. It is important for us to enlarge our narrowly focused view of sexuality regarding the person with a disability. We need to view him or her—even an individual who is retarded intellectually—as having sexual needs and characteristics common to the non-disabled population.

This is not easy, for most of us tend to vacillate from one extreme to the other. We may point out our children's deviation and lack of judgment, instead of looking at their common human needs. We see sex as dangerous and adding to their already anxious lives.

Parents as well as professionals sometimes stick to the belief that sex is private, so let's not talk about it. We constantly ask, "Will our child be able to control impulses so she or he will not embarrass us socially, be exploited or get into trouble?"

The truth is that the more comfortable children are with their sexuality, the better they can deal with their feelings. How can we ask our sons and daughters to be responsible for their behavior—sexual or otherwise—if we allow, and almost guarantee, their ignorance by not telling them the truth about themselves? We must not believe the myth that people with disabilities are asexual or uncontrollable and that their sexual feelings must be ignored or confined.

In our effort to convince the schools that this subject should be taught, we could use the term "social-sexual training" instead of "sex education"... [T]he ultimate goal is to help the person with a disability fit into society and feel self-confident. Sex education can deal not only with sex per se, but with social relationships and emotional fulfillment.

The question should not be whether our child should be given sex information, but when, how and by whom? Sex education includes learning about relationships, body feelings, stimulation, control, and male and female roles.

Sex education does not breed experimentation, nor stimulate the student to sexual activity. Rather, knowledge can act as a deterrent, for it teaches control. It cannot begin too early. Children learn only what they are capable of comprehending—but it can be too late if we wait too long. **EP**

Betty Pendler, a New York City resident, is a member of the EXCEPTIONAL PARENT Editorial Advisory Board and the New York State Developmental Disabilities Planning Council. She has contributed numerous letters and articles to EXCEPTIONAL PARENT over the last 25 years. Lisa, now 40, lives with seven other adults in a nearby group home.

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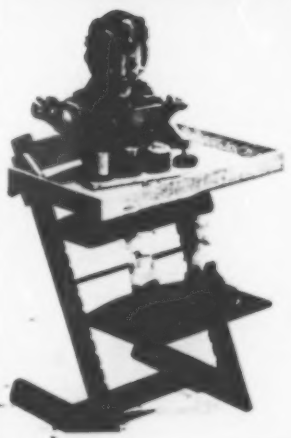

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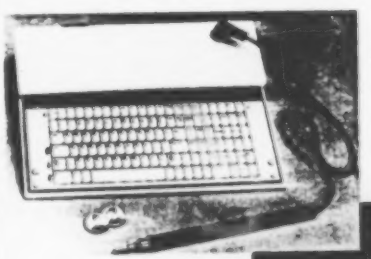

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Health

A PARENTS' GUIDE TO ENTERAL NUTRITION
PART TWO: Care of the Stoma and Tube

The surgical opening through which a gastrostomy tube (g-tube) or jejunostomy tube (j-tube) enters the stomach or small intestine is called a stoma. The stoma often becomes moist from gastrointestinal secretions. This may cause the skin to break down, ooze and be sore. Proper care of the stoma site can help to avoid such problems.

It is important to keep the skin around the tube or g-button as dry as possible with a gauze pad or dressing. The dressing should be changed as often as it becomes moist or soiled. This could be once a day or as often as 20 times a day. Tape is not usually used because with constant changes, it may pull and break the skin. Use of an antibiotic ointment may be useful if the site tends to become easily infected. Since some parents find that the dressing also protects and cushions the skin around the tube, they continue to use a dressing whether the site is moist or not.

ABOUT THIS SERIES:
This is the second of several articles on enteral nutrition. Further articles will cover topics such as formulas and nutritional needs, positioning, oral motor difficulties and making the transition to oral eating.

The skin should be snug around the tube. This helps the tube stay in place and minimizes leakage of secretions. If the skin around the tube appears very pink and bleeds, you should inform your child's doctor. Often the doctor will treat this tissue with a silver nitrate application to seal the blood vessels, which prevents bleeding.

Your doctor may order consultation with an enterostomal therapist (ET). This is usually a nurse who has a wide knowledge of methods and products that can be used to keep the stoma healthy. The cost of ET services is often covered by health insurance policies.

When a tube falls out

A g-tube is usually anchored inside the stomach by a balloon at the tip of the tube just inside the stomach. Frequently, once a g-tube has been in place for some time, stomach acid will cause the balloon to deteriorate and deflate, and the tube will fall out. Because the stoma may close within an hour or two, your child's physician or nurse will have provided a replacement g-tube and shown you how to reinsert it.

Jejunostomy tubes, on the other hand, can be reinserted and positioned only by a physician. If a j-tube falls out, don't panic, just call your child's doctor. As long as the doctor gets the message immediately, he or she can make arrangements to reinsert the tube, based on his or her schedule and the length of time your child can go without fluids.

Stomach distention

Sometimes a child will end up with air in his or her stomach. This can

continued on page 73

Jaw Joint Mobility

Oral motor therapist Debra Beckman, M.S., C.C.C.-S.L.P., works on jaw movement with three-year-old Scott McNally.

Children who neither talk nor eat orally are at increased risk of developing temporomandibular, or jaw joint, contractures, a condition in which the small muscles around the joint shorten from lack of movement. This changes the position and movement of the base of the tongue, making it difficult or impossible for the child to move respiratory and oral secretions out of the throat or airway by swallowing or coughing. This puts a child at increased risk of choking, congestion and pneumonia.

Jaw movement can be improved through oral motor therapy by an occupational or speech therapist who has been trained in these techniques. It is easier to prevent loss of movement than to restore it. It can be difficult to make this case to health insurance providers; however, because of the risk of movement loss, it is important to advocate for your child to receive therapy for continued movement of these important muscles when he or she is not eating orally.

845

Your Advocate

The Division for Early Childhood (DEC)

The **DIVISION FOR EARLY CHILDHOOD (DEC)** of the Council for Exceptional Children (CEC) is a non-profit membership organization advocating for individuals who work with or on behalf of children with special needs, birth through age eight, and their families. Founded in 1973, the Division is dedicated to promoting policies and practices that support families and enhance the optimal development of children. Children with special needs include those who have disabilities, developmental delays, are gifted/ talented, and are at risk of future developmental problems.

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continued from page 70

cause discomfort, particularly if the child cannot belch. If the child is obviously uncomfortable and his or her stomach is distended (bloated), you can vent air through the g-tube by opening the end and holding it up, away from the abdomen. You will hear the gas escaping. Because fluid may come up with the air, it can be helpful to attach the gavage tube, into which you pour formula for feedings, to the end of the g-tube. Then, any liquid that comes up will usually flow back into the stomach. This is important because this liquid contains enzymes and electrolytes the body needs.

If the child's stomach remains distended after venting, it may indicate an intestinal obstruction around which the food cannot flow. Usually, this is the result of the g-tube having moved through the stomach along with the flow of the food, causing the balloon on the tip of the tube to become lodged in the small bowel. This is not usually a serious situation. In most cases, your child's physician will first x-ray tube placement, and then pull back gently on the tube until it comes back into the stomach, whereupon the stomach distention will slowly resolve.

Very rarely, stomach distention occurs as the result of some other type of intestinal obstruction. This would be a serious problem. It is important to develop an advance plan with your child's physician to handle this situation should it occur. Most children never experience this problem; however, children who experience it once are at a much greater risk of it recurring. **EP**

Lee Barks, R.N., M.N., A.R.N.P., is the president and owner of Developmental Health, Inc., a firm that provides consulting services to rehabilitative and long-term-care programs. She also works as a pediatric nurse practitioner at Pediatrics Plus, a private practice in Orlando, Florida, and as a consultant to the early intervention program at the Arnold Palmer Hospital for Children and Women, also in Orlando. Lee lives near Orlando with her husband and teenage son and daughter.

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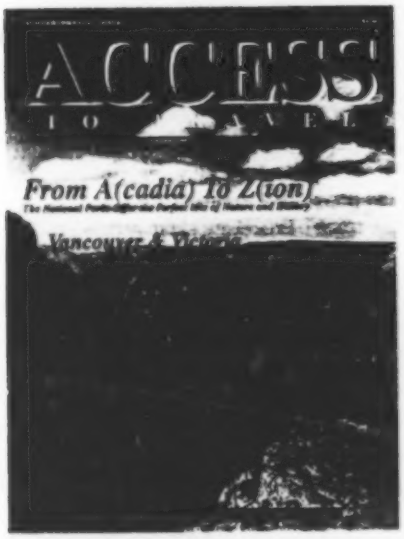

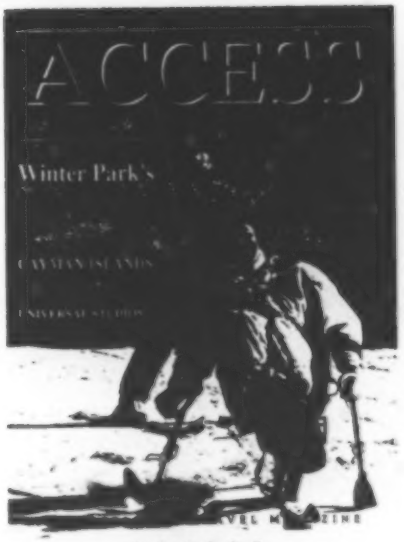

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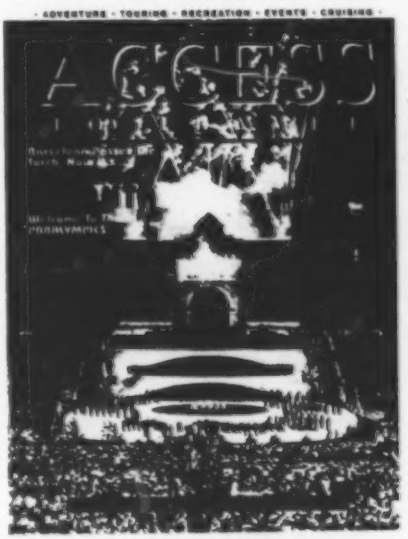
ACCESS To Travel has taken its readers down the rapids on the Colorado River, snorkeling in the Cayman Islands, and for winter recreation in the Rockies. We've had familiy fun at a dude ranch in Montana and took the kids for a ride with E.T. at Universal Studios.



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Can Magnesium Sulfate Prevent Cerebral Palsy?

A new study looks for answers

by Lynn Bentz and Robert Mittendorf

Cerebral palsy is the most common, severe childhood motor disability for which there is no prevention or cure. The most important predictor of cerebral palsy is very low birthweight (less than 3.3 pounds). Because of recent technical advancements in care, more very small babies are surviving, thus, the prevalence of cerebral palsy has increased by as much as 20 percent in the past three decades.

Two recent studies suggest that pre-delivery use of magnesium sulfate may prevent cerebral palsy and intracranial hemorrhage (bleeding in the brain) in very-low-birthweight infants.* Both studies were retrospective (backward-in-time) investigations, meaning that the researchers compared the incidence of cerebral palsy and intracranial hemorrhage in infants whose mothers had been given magnesium sulfate incidentally—that is, not as part of a formal research study—with the incidence of these conditions in infants whose mothers had not happened to receive the drug.

Magnesium sulfate, a drug that has been found safe for both mothers and babies, is commonly used in pregnant women with severe preeclampsia (also known as toxemia or pregnancy-induced hypertension)—a condition involving edema (swelling of the hands and face), unintentional weight gain (in excess of two pounds a week), elevated blood pressure and proteinuria (protein in the urine). Preeclampsia may develop into eclampsia, which is characterized by the occurrence of seizures; magnesium sulfate acts as an anticonvulsant. The drug is also used to suppress premature labor.

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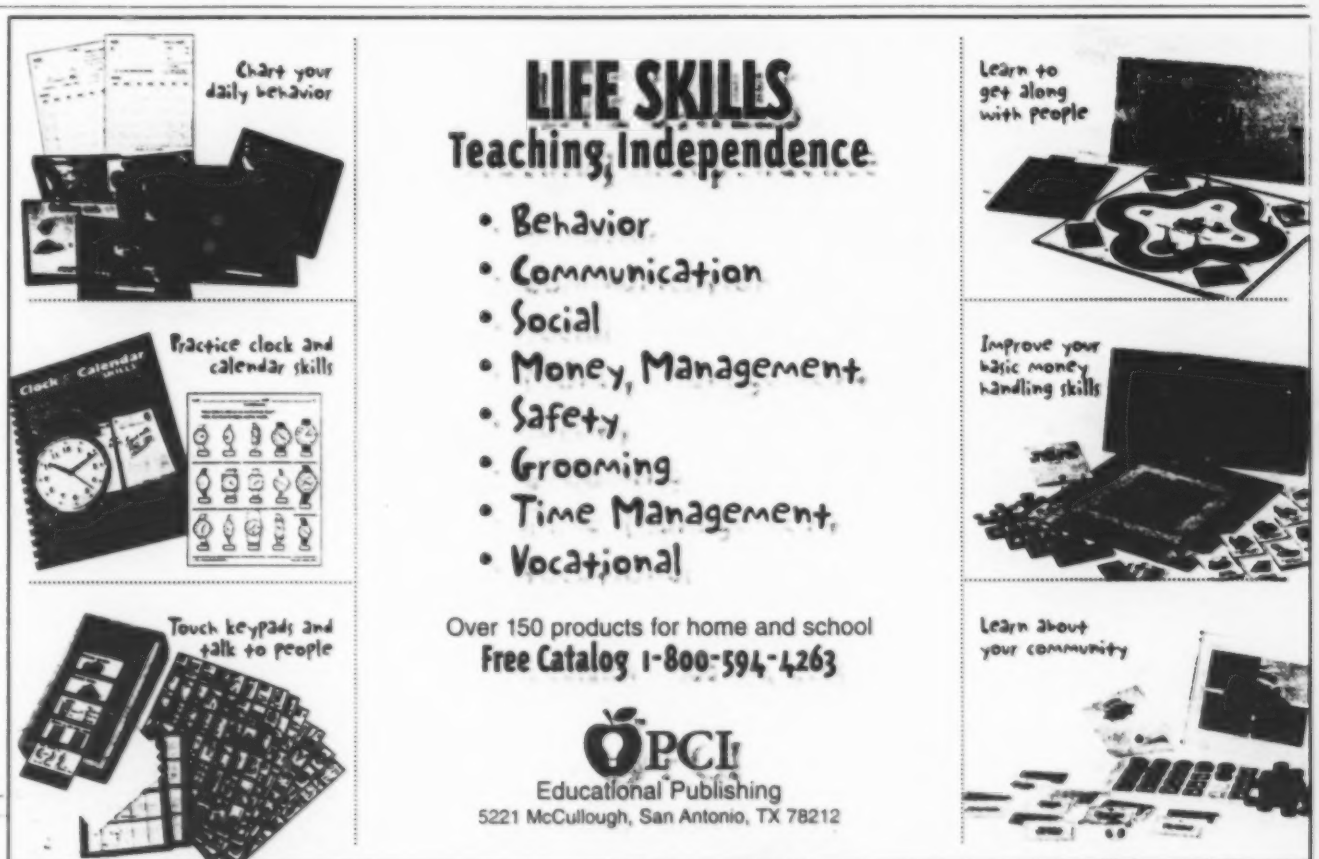
*Nelson, K.B. & Grether, J.K. 1995. *Can Magnesium Sulfate Reduce the Risk of Cerebral Palsy in Very Low Birthweight Infants?* PEDIATRICS, 95:263–9; Kuban, K.C.K., Leviton, A., Pagano, M., Fenton, T., Strassfeld, R. & Wolff, M. 1992. *Maternal toxemia is associated with reduced incidence of germinal matric hemorrhage in premature babies.* JOURNAL OF CHILD NEUROLOGY, 7:70–6.



Circle #72 849

In the fall of 1995, funded by the United Cerebral Palsy Research and Educational Foundation, the University of Chicago began the first-ever prospective (forward-in-time) study to determine whether magnesium sulfate given to pregnant women prior to delivery prevents cerebral palsy or intracranial hemorrhage in their infants. Pregnant women who are admitted to the University of Chicago Labor and Delivery Suite for premature labor, and who agree to become a part of the study, intravenously receive either magnesium sulfate or another drug that is thought to be equally effective for stopping labor. Medication is given until premature labor is successfully suppressed or until the baby is delivered. Pregnant women whose labor is too far along to be successfully halted receive intravenously either a single dose of magnesium sulfate or the same amount of normal saline solution, which is not a drug.

After delivery, the babies are given ultrasound examinations of the head to determine whether any bleeding or deprivation of blood flow has occurred in the brain. The ultrasounds are done several times—at the ages of one week, two weeks and one month.

Developmental follow-up and cerebral palsy screening are done after the babies are discharged from the hospital. Parents are mailed a questionnaire asking them to assess their infants' activities. Appointments for developmental milestone assessment and cerebral palsy screening are scheduled for nine months, 12 months and 18 months of age. Parents who keep these appointments are paid with funds from a grant awarded by The University of Chicago Hospital's Home Health Care Program.

If magnesium sulfate is shown to reduce the prevalence of intracranial hemorrhage and cerebral palsy, subsequent studies would be needed to establish the optimal dosage. However, before the scientific community can endorse any substantial change in the clinical practice of obstetrics—such as wide-spread pre-delivery use of magnesium sulfate for very-low-birthweight infants—its effectiveness must be established by studies such as this. **EP**

This is one of a series of articles prepared in collaboration with the National Perinatal Association (NPA, 3500 E. Fletcher Ave. Ste. 209, Tampa, Florida 33613-4712). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time of birth) health issues from preconception through infancy. Dr. Robert Mittendorf and Lynn Bentz, R.N., B.S.N., work in the Department of Obstetrics and Gynecology at the University of Chicago. Mittendorf, Director of Health Studies, and Bentz, a research nurse, supervise the MAGnet Trial, and collaborate with Dr. Robert Covert, Dr. David Yousefzadeh, Dr. Tamar Ben-Am, Dr. Jocelyn Kohn, Dr. Atef Moawad, Dr. Judy Hibbard and Dr. Nancy Roizen.

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WHAT'S HAPPENING

Books

In collaboration with parents and staff members, the Thames Valley Children's Centre, a rehabilitation center serving children and young adults with disabilities in London, Ontario, has published two books on two sensitive topics—toilet training and sexuality. Each book is written in a non-threatening and humorous way, accompanied by delightful illustrations.

• *Toilet Training With Your Special Child* by Dorothy Harris and Michelle Gilpin with illustrations by Steve Stanley. This book was developed in response to common questions and concerns about toilet training for a child with a disability. It is an easy to follow guide that combines parents' experiences with clinical information. It covers such topics as: determining if your child is ready, preparing your child for toileting, understanding reasons for setbacks, recognizing problems with constipation, using rewards and incentives, night time dryness, toilet training for older children and adapted seats.

• *Caution: Do Not Open Until Puberty! An Introduction to Sexuality for Young Adults with Disabilities* by Rick Enright with illustrations by Sara L. Van Hamme. Though written for young people with spina bifida, cerebral palsy, spinal cord injuries, muscular dystrophy and other mobility disorders, parents and professionals will also find this book very helpful. In author Rick Enright's words, "It is important for every person to understand their own body, how it works, and what to do when something is not right."

Caution: Do Not Open Until Puberty! is an attempt to break the silence that seems to prevent an open discussion of sexuality with adolescents with disabilities and their families. It answers questions in a friendly and humorous manner.

Each book is available for $9.95 ($8.95 if ordering three or more copies), plus shipping and handling (USA orders: $3.50; $8 if ordering three or more copies; Canadian orders: $2.50; $6.75 if ordering three or more copies; International orders: $5.50; $14.75 if ordering three or more copies). Send order and payment in U.S. or Canadian dollars to: Devinjer House, P.O. Box 130, Sparta, Ontario, CAN N0L 2H0. Please allow six weeks for delivery.

Helping Parents Help Each Other

Parenting is a difficult job. It's even harder when your child has a serious illness or disability. While friends, relatives and professional caregivers can empathize, parents often feel that the only people who can truly understand the emotions and stresses that come with parenting a child with special needs are those who have shared similar experiences.

The Friends' Health Connection (FHC) is an international, non-profit organization that brings together families who have children with similar illnesses or disabilities for one-to-one support. Matches are made on the basis of the child's age, health problems, personal background, symptoms and interests. Participants share experiences, ask each other questions and share comfort and encouragement. One parent states, "I had networked with several organizations, but it wasn't until FHC that I found a match. Ironically, the person I was matched with lives only 30 minutes away; we are working together to battle our kids' illnesses."

For more information about FHC, call (800) 483-7436, or visit their World Wide Web site at http://www.48friend.com.

FHC founder Roxanne Black, 25, was diagnosed with lupus as a teenager.

FUNNY AS A CRUTCH by Frank Bernard, Jr.

SHARPTON, I CAN'T STAND WHEN PEOPLE WHO DON'T EVEN KNOW ME CALL ME "SPECIAL".
HOW DOES SOME TOTAL STRANGER KNOW WHETHER OR NOT I'M SPECIAL?
I MEAN, LET THEM SEE ME BELCH THE ALPHABET, THEN THEY CAN CALL ME SPECIAL!

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Circle #53

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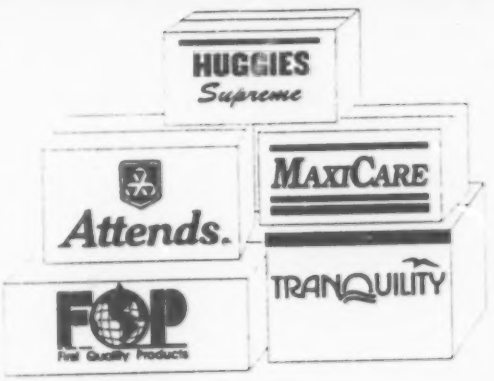
- Referrals to advocacy and support groups.
- Referrals to religious education programs.
- Lists of religious materials.

Bethesda offers workshops and resources to help you build parish ministries which fully include persons with disabilities and their families. For more information call 1-800-369-INFO.

Circle #26

BLADDER CONTROL PROBLEMS?



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Circle #102

Learning Your ABCD's

Matthew's legacy helps parents find answers.

Eva Tameling founded ABCD after her struggle to help her son Matthew.

Just as inspiration is the mother of invention, Eva Tameling is the mother of ABCD— Assistance for Babies and Children with Carnitine Deficiency. Her inspiration: her son, Matthew.

At five months, symptoms led doctors at Chicago's Children's Memorial Hospital to believe that Matthew had a metabolic problem. Two days later, Matthew became seriously ill and almost died. After being stabilized, he was diagnosed with Pompe disease, a terminal condition that affects the brain.

Stunned, Eva set out to find some relief for her son's symptoms. Her search led to a metabolic specialist, the first to suggest that relief lay not in treatment of Pompe disease, but from a secondary condition: carnitine deficiency. Eva's skills and experience as a successful attorney served her well in her battle for knowledge, recognition, and treatment that ultimately resulted in the founding of ABCD.

Carnitine is a natural substance that helps turn ingested food into energy. Produced by the body and found in foods such as red meat and dairy products, carnitine helps infants gain weight and build muscle and organ tissues. It also cleanses the body by removing cellular waste products. Eva was told that carnitine deficiency is often found as a secondary condition to other metabolic disorders. Unlike Pompe disease, carnitine deficiency *is* a treatable condition, although it can be fatal if ignored. Undiagnosed carnitine deficiencies have been linked to cardiomyopathy, severe developmental disabilities and, according to some experts, as many as 25 percent or more cases of sudden infant death syndrome.

The specialist's suspicions about carnitine deficiency proved correct. Matthew was quickly given prescription levocarnitine, and his quality of life improved dramatically. "He was able to sit up, raise his arms, play with his rattle and crib toys, and respond to me and other members of his family— things normal for most babies," Eva says.

... AS MANY AS 450,000 INFANTS AND CHILDREN COULD BE SUFFERING NEEDLESSLY FROM UNDIAGNOSED METABOLIC PROBLEMS.

Overjoyed to see the change in him, Eva says "To be able to remember him the way he was after he received treatment is a tremendous gift which I treasure." Though expected, sadly, Matthew died that spring. The original diagnosis had put life expectancy at only three additional months. Carnitine deficiency treatments added a precious month to that.

Soon after, Eva founded ABCD. The group's mission: Increase the awareness of carnitine-dependent disorders within the medical and consumer communities, and provide guidance to families of affected children.

ASSISTANCE FOR BABIES AND CHILDREN WITH CARNITINE DEFICIENCY

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While detecting the deficiency is as simple as a blood test, knowing *how* to spot evidence of carnitine deficiency is difficult because many children show no outward symptoms. Others display poor muscle tone and coordination, lethargy and unusual weakness. In fact, Eva claims, only a few of those with the condition are actually diagnosed. Based on the results of a survey of pediatricians conducted for ABCD in 1995 by the Gallup organization, as many as 450,000 infants and children could be suffering needlessly from undiagnosed metabolic problems.

Another reason for the low number of diagnosed patients is that doctors simply are not aware of the condition. In the same Gallup survey, only 52 percent of the physicians surveyed were familiar with carnitine deficiency, and of those only 43 percent knew that blood tests were necessary to confirm a diagnosis. Metabolic disorders are second only to child abuse as the most difficult health condition to diagnose.

Yet testing for these disorders can begin at birth. Neonatal screening can prevent the needless fear and frustration of undiagnosed disorders endured by children and their families. "We have experienced first-hand how difficult it is to obtain the correct diagnosis of a metabolic condition," says Angela Gaine of Goshen, NY. It took one full year, four misdiagnoses and a dozen doctors before her son, Daniel, was properly diagnosed.

Although Daniel's primary condition is still unknown, "the diagnosis of Daniel's carnitine deficiency unlocked one part of the mystery surrounding his condition," Gaine says. "Now we can search for the key to the rest of it."

In efforts to sidestep the long ordeal experienced by the Gaines and many other families across the nation, ABCD is currently building a coalition of interested parents, metabolic disorder groups, doctors, health policy makers and others supportive of nationwide neonatal testing. "We are committed to continued educational outreach on the symptoms, detection and treatment of carnitine deficiency," Eva says. The neonatal screening test can detect 38 metabolic disorders at a cost of less than $20.00. "Every child," Eva declares, "deserves to have this test at birth."

ABCD is focusing its efforts on convincing health policy makers to support widespread neonatal screening to identify newborns with metabolic disorders. Screening done early in life can prevent brain damage and retardation. For this reason, ABCD believes neonatal screening should be considered an important preventive measure. The organization is active in Washington, D.C., meeting recently with Illinois Representatives Henry Hyde and Dennis Hastert to discuss the possibility of a bill mandating metabolic screening. Its quarterly newsletter provides parents and professionals with updates on discoveries and mandates.

As for Eva, "When the efforts of ABCD have saved even one child's life," she says, "the suffering of my family— and families of similar experience— has served a positive purpose."

Making Doctors Aware:

How is the A/F ratio calculated?

When carnitine performs its different roles in the body, it is sometimes "free carnitine" and sometimes bound to other compounds and called acylcarnitine. Even if the total carnitine is present in adequate amounts, an alteration in the relationship of free carnitine to acylcarnitine may indicate that the child would benefit from carnitine treatment. Thus, both total and free carnitine are often directly measured and the difference between the two values is termed acylcarnitines. Subtract the free carnitine from the plasma total which gives you the plasma acylcarnitines. Divide the plasma carnitines by the free carnitine. This gives you the plasma A/F (acyl to free carnitine) ratio.

Reprinted from ABCD's free quarterly newsletter. To receive the newsletter, contact ABCD, 1010 Jorie Blvd., Suite 234, Oak Brook, IL 60521-2240, or call (800) 554-2223 or (630) 571-9608.

Detecting Carnitine Deficiency

While studies show that metabolic disorders are difficult to recognize, there are certain signs to look for:

- Very poor muscle tone and coordination
- Chronic vomiting and fever
- Severe feeding problems
- Failure to thrive
- Little weight gain and/or weight loss
- Lethargy and unusual weakness
- Recurrent infections or flu-like symptoms
- Seizures or adverse side effects from seizure medication
- Enlarged spleen or liver
- Cardiomyopathy

While your child may have these symptoms, remember that only a blood test can confirm a diagnosis. Ask your pediatrician to test your child's carnitine plasma level—also called the plasma A/F ratio (see box above). Contact Assistance for Babies and Children with Carnitine Deficiency (ABCD) at 800-554-ABCD, or (630) 571-9608 for more information and support.

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Your baby looks normal... yet you know something is wrong.

Your child cries so softly and so rarely...seems to have little interest in eating or nursing...doesn't respond to people or objects...doesn't recover from colds... vomits frequently...is limp and always tired.

If your newborn or young child has some of these symptoms, he or she may have CARNITINE DEFICIENCY.

Testing is simple and inexpensive. Treatment is available. Delayed diagnosis has been linked to severe developmental disabilities such as mental retardation. Carnitine deficiency caused by metabolic disease can be fatal if untreated.

What is it? Carnitine is a naturally occurring substance that helps turn the food we eat into energy and protects the body from accumulating toxins that interfere with energy production. Babies and young children lack the enzyme to make their own supply of carnitine, but in most cases obtain the necessary supply from dairy products, breast milk, infant formula and red meats in their diet. Infants and children may be carnitine deficient due to a failure to transport carnitine into the cells. This is called primary carnitine deficiency. A deficiency resulting from poor dietary intake or a metabolic disease which depletes the body's stores of carnitine is called secondary carnitine deficiency.

What are the symptoms? Very poor muscle tone and coordination, chronic vomiting and fever, severe feeding problems, failure to thrive, little weight gain and/or weight loss, lethargy and unusual weakness, recurrent infections, flu-like symptoms, seizures or loss of seizure control, liver dysfunction and poor cardiac function.

What can you do? Consider the possibility that your child has a metabolic disorder if traditional treatments for a health problem don't seem to be working. Ask your pediatrician to check your child's carnitine plasma level. Be aware that carnitine deficiency is a symptom of metabolic disorders and further examination by a metabolic disease specialist is needed. Treatment for carnitine deficiency is simple and fast acting in acute cases. Contact Assistance for Babies and Children with Carnitine Deficiency for more information and support.

A parent-founded organization which serves as a source of support and guidance for the families of carnitine deficient children.

A B C D

ASSISTANCE FOR BABIES AND CHILDREN WITH CARNITINE DEFICIENCY

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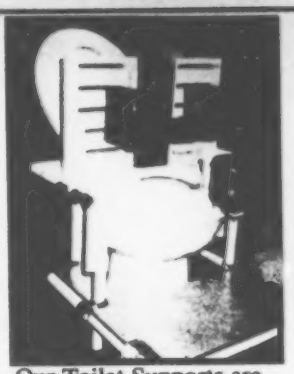
Circle #27



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ASK THE DOCTOR

Pervasive Developmental Disorders

by David Hirsch, M.D.

Q My five-year-old son was recently diagnosed with "pervasive developmental disorder" (PDD). Doctors say he is "autistic-like." He had an uncomplicated birth and has been very healthy. We have no family history of this condition or anything similar.

My son appeared to develop normally until about 18 months of age, when he seemed to become more withdrawn. He no longer seemed interested in toys and stopped communicating with his sister or me, preferring to be alone. If anything in his daily routine is changed, he gets very upset. He has not had any significant cognitive development since the age of three.

His disability would be so much easier to deal with if we had some help from the state agency that assists individuals with developmental disabilities. However, because my son has not been diagnosed with autism, mental retardation, epilepsy or cerebral palsy, he does not qualify for services.

I have been talking to some parents of children who have been diagnosed with autism. Their children seem very similar to my son, but because they have the label "autism," their children qualify for aid. I feel this is unfair. What can I do?

A I agree it is unfair to deny your son services, especially when the diagnosis of autism—as opposed to "autistic-like" and other types of PDDs—is often very subjective.

All PDDs have common symptoms of varying severity. These often include abnormal language and communication skills; poor social interaction ability; repetitive, stereotypic behaviors and resistance to change in routines. Some children also exhibit abnormal responses to loud noises, visual stimuli, touch, tastes or smells.

Individuals with PDDs have a wide range of intellectual abilities—from severe mental retardation to normal intelligence. A higher incidence of attention deficit disorder, seizures and behavioral and emotional disorders are also associated with PDD.

PDDs occur as often as 15 per 10,000 births and are four times more common in boys than girls. Autism is the most widely recognized and extensively studied PDD. Other PDDs, which may be difficult to distinguish from autism, include Asperger syndrome, atypical autism, Rett syndrome, childhood disintegrative disorder (Heller syndrome) and pervasive developmental disorder-not otherwise specified (PDD-NOS).

For a diagnosis of autism, a set of specific criteria must be satisfied. These criteria, or symptoms, are listed in a diagnostic manual called the DSM-IV. The DSM-IV, published by the American Psychiatric Association, contains the official diagnostic classifications of both mental illnesses and neurological conditions such as autism. The DSM-IV classifies disorders for diagnosis, therapy and research. Also, as you have discovered, a DSM-IV classification may be used to determine eligibility for various services.

DSM-IV criteria for autism include: impairment in social interaction as manifested by impairment of nonverbal behaviors used to regulate social interaction (such as eye contact and gestures); failure to develop peer relationships appropriate to developmental level; lack of social or emotional reciprocity (give and take); delay in or lack of spoken language or, when adequate speech ability exists, impairment in the ability to begin or sustain conversations; lack of pretend play appropriate to age level; repetitive and stereotyped patterns of behavior such as hand- or finger-flapping or twisting or complex whole body movements; and inflexible adherence to specific, purposeless routines or rituals.

Although these DSM-IV criteria are very specific, determining the presence or severity of certain symptoms is a judgment call on the part of the professional doing the evaluation. It also depends greatly on the evaluator's training and experience with autism. Based on your description, it sounds like your son's symptoms may fit the criteria for a diagnosis of autism. I would recommend that you have him reevaluated by a qualified pediatric psychiatrist, developmental pediatrician or developmental psychologist.

For more information on autism and PDDs, contact the Autism Society of America (7910 Woodmont Ave., Ste. 650, Bethesda, MD 20814; 800/328-8476; 301/657-0881; 301/657-0869, fax) or the Autism Society of Canada (129 Yorkville Ave., #202; Toronto, ON CAN M5R 1C4; 416/922-0302; 416/922-1032, fax). A great deal of information is also available on the Internet; for links to on-line resources, you may wish to check out the Autism Resources Home Page (http://web.syr.edu/~jmwobus/autism/). **EP**

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).*

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Hotel Single/Double $110 per night (plus tax). No charge for children under 17 sharing a room with their parents. Additional adults in the room will be an additional $25 per adult per night. As a convenience to you, the special room rate is available from Monday night, Oct. 14, through Tuesday night, Oct. 22, 1996. Call (714) 750-4321 and ask for Forum '96.

Airfare We have arranged special discounts on American and Southwest Airlines. On American save 5% on lowest applicable fares, or 10% on lowest, unrestricted coach fares, with 7-day adv. purchase. On Southwest, save 10% on their published everyday low fares. Discounts are on travel between Oct. 11 and 23, 1996. Call our official travel agency, Conventions in America (CIA), at (800) 929-4242 and ask for Group #504; or, call American at (800) 433-1790, Starfile # S6806MC; Southwest at (800) 4335368, ID#444742GR. For special rates on Alamo Rent A Car and Amtrak call CIA.

Conference Aide Save up to 70% on your conference tuition by working as an aide at the beginning and end of each day and at breaks. There are also positions available for Child Care Aides. Check box labeled "Conference Aide" on the registration form, indicate which type of aide you would like to be and include a check for $50 (tuition does not include Saturday's family dinner). Selection is on a first-come, first-served basis. Act now; positions will fill quickly.

Cancellations **Requests must be in writing.** Refunds will be given on requests postmarked no later than 14 days prior to the conference. A $35 per person processing fee will be deducted from all cancellations. Any request postmarked within 14 days of the conference will not be refunded unless accompanied by a doctor's note explaining why registrants cannot attend. If Forum '96 is cancelled by EXCEPTIONAL PARENT, tuitions will be refunded in full.

Questions?

For conference information, call IBH at (415) 851-8411 For exhibit information, contact EXCEPTIONAL PARENT, PHONE: 800.EParent.

FAX: 201.489.1240. EMAIL: epmag12@aol.com

Agenda

Thursday—October 17

7:30–9:30 PM Welcome Reception in Exhibit Hall:
Meet the Exhibitors, EXCEPTIONAL PARENT staff, and fellow attendees.

Friday—October 18

9:00–10:15 AM Welcome Address and Keynote Panel I:
Future of Family Healthcare for Those with Disabilities

10:30-11:30 AM Keynote II:
The Role of Sports and Play in the Development of Children with Special Needs

11:30 AM–1:00 PM Cash Lunch (on your own) in Exhibit Hall

1:00–2:45 PM Session I: Workshops & Roundtables

Estate Planning for Families	Ask the Doctor	Transporting Children with Disabilities	Fathers of Children with Special Needs	Inclusion: Pros & Cons	Transitior Services

3:00–5:00 PM Session II: Roundtable Discussion

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

Saturday—October 19

8:30–10:00 AM Keynote Panel Discussion:
Who Should Be President of the United States?

10:15–12 NOON Session III: Workshops & Roundtables

People with Disabilities: Religion & Faith	What Happens When My Child Grows Up?	Bringing New Products to Market	Family Issues	Alternate Therapies	Children with Carnitine Deficiency

12 NOON–1:30 PM Cash Lunch (on your own) in Exhibit Hall

1:30–3:00 PM Session IV: Workshops & Roundtables

Children with Autism	Children with Down Syndrome & Mental Retardation	Children with CP, Muscular Dystrophy & Spina Bifida	Children with Hearing & Visual Impairments	Children with ADHD or Learning Disabilities	Children with Rare Disorders

5:00–? PM 25th Anniversary Dinner & Disneyland
A fun evening of food, mingling, entertainment....and then rides and games in Disneyland. (Transportation not included)

Agenda

Sunday—October 20

8:30–10:15 AM Session V: Workshops & Roundtables

Making it Easier to Travel	Ask the Doctor	Role Models	Fathers of Children with Special Needs	Inclusion: Pros & Cons	Disability Issues & the Hispanic Community

10:30–12 NOON Special Closing Forum for Parents and Children

Optional Events

Thursday—October 17

2:00–4:00 PM Pre-Conference Workshops ($45 per person)
(Choice of one)

Funding & Where to Find It in Calif.	Seating & Positioning Issues

Friday—October 18

7:00–9:00 PM Prominent Guest Panel Discussion: ($25 per person)
Well-known Personalities who either have Disabilities themselves or have Family Members with Disabilities or Special Health Care Needs

Registration

The following are the registration hours attendees can check into the conference.

Thurs.—10/17	1:00–9:30 PM
Fri.—10/18	7:30 AM–7:30 PM
Sat.—10/19	7:30 AM–3:00 PM
Sun.—10/20	7:30–9:00 AM

Exhibit Hall

The following are the hours the Exhibit Hall will be open.

Thurs.—10/17	4:00–7:00 PM
(Conf. Attendees Only)	7:30–9:30 PM
Fri.—10/18	10:30 AM–5:00 PM
	7:00–9:00 PM
Sat.—10/19	9:00 AM–3:00 PM

Exhibit Hall Admission

Free to all conference attendees. Exhibit Hall Only Passes: $5 per day (children under 2: free). Purchase passes at the Exhibit Hall.

NOTE: All events and schedules are subject t change.

Invited Faculty

Honorable Edward M. Kennedy,
United States Senator
Ranking Member/Senate Committee on Disability Policy

Honorable Bill Frist,
United States Senator
Chair/Senate Committee on Disability Policy

James May, MA, MEd*
Project Director, National Fathers' Network

Rick Rader, MD*
Director, Institute for Developmental Medicine
Orange Grove Center

Ginny Thornburgh
Director of the Religion & Disability Program
National Organization on Disability

Judith E. Heumann
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US Department of Education

Zina Bethune, Artistic Director*
Bethune Theatre Dance & Dance Outreach
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David Hirsch, MD*
Pediatrician, Columnist
Phoenix Pediatrics

Stanley I. Greenspan, MD
Clinical Prof. of Psychiatry & Behavioral Pediatrics/George Washington Univ. Med. Sch.

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Address _____

City _____ State _____ Zip _____

Phone ( ) _____ Fax ( ) _____

2nd Adult:

Name _____

3rd Adult:

Name _____

4th Adult:

Name _____

Children: (See Special Needs box)

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Name _____ Age _____

Conference Tuition Includes:

- Admission to all roundtables, workshops, and events
- Unlimited admission to the exhibit hall
- 25th Anniversary Family Dinner Get-Together
- Saturday evening Disneyland Park pass
- Continental breakfast each morning
- Thursday evening Welcome Reception in exhibit hall
- Refreshments at breaks
- All conference materials
- A certificate of conference participation
- A conference T-shirt
- Discount coupon for the next EXCEPTIONAL PARENT Conference
- $5-discount off your next EXCEPTIONAL PARENT Library purchase

Special Needs???

1) Will you require wheelchair accessible transportation? _____

2) What other special needs do you have? _____

_____

_____

Join us for our 25th Anniversary Dinner and an Evening in Disneyland!

Saturday, October 19
Anaheim Hilton & Towers

A fun evening of food, games, entertainment, rides and games in Disneyland included in tuition with full registration for conference.

Extra tickets:
$50 for Adult, $35 for Child

Transportation to Disneyland not included

Fees:	Early postmarked by 7/31/96	Regular postmarked after 7/31/96	
❑ 1st Adult	$165	$245	$___
❑ 2nd Adult	$125	$195	$___
❑ 3rd Adult	$95	$150	$___
❑ 4th Adult	Free	Free	$___
❑ Each child under 14	$65 ($65 x # of children)	$75	$___
❑ Conference Aide	$50	$50	$___
See "Conference Aide" under the Conference Information section Check one: ❑ Administrative Aide ❑ Childcare Aide			
❑ Special Family Rate	$350	N/A	$___
Receive this special rate when you register and pay for your family of four (2 adults and 2 children under 14) by 7/31/96			

Extra-Cost Events:

❑ Pre-Conference Workshop (Thurs) ($45 x # of attendees) $___

❑ Fri. Evening Prominent Guest Panel ($25 x # of attendees) $___

SAT. DINNER/DISNEYLAND PASSES (for non-conference attendees)

❑ Adult ($50x ____) ❑ Child ($35 x ____) $___

TOTAL PAYMENT ENCLOSED (U.S. funds) $___

All tuitions must accompany registration

METHOD OF PAYMENT

❑ Check enclosed made payable to Exceptional Parent (U.S. Bank)

❑ Visa ❑ Mastercard

Card # _____ Exp. date _____

Signature _____

Cardholder name (Print) _____

3 Ways to Register

• 120 State St. Hackensack, NJ 07601 ☎ 415.851.8411 fax 415.851.04

forum '96
EXCEPTIONAL PARENT
120 State Street
Hackensack, NJ 07601-5421

CENTER FOR CHILDREN WITH CHRONIC ILLNESS AND DISABILITY

Children's Health Notes

Getting Through Adolescence:

Develop Programs That Promote Resilience

Resiliency research provides a clear picture of those things that protect youth at risk—including youth with disabilities—against an array of bad outcomes. Understanding those factors that improve the outcomes of those at risk should help community leaders design better programs for youth with disabilities.

Resilient adolescents are not invincible superbeings. They do not display an unusual amount of happiness, life satisfaction or stress-related health problems. They are not immune to life's challenges or difficulties. When faced with ongoing emotional or physical distress, these youth remain socially competent. Sadness and unhappiness in stressful circumstances is expected; remaining productive despite these effects is a hallmark of resilience.

There have been a number of consistent findings across a wide variety of studies that have explored risk and protective factors for children and youth with disabilities and their families.

Three qualities appear in youth with disabilities who succeed. They have appealing temperaments, grow up in the presence of one or more caring adults, and are involved in a church, school or other caring organization.

These qualities—protective factors—may have a more profound impact on resilient behavior in childhood, adolescence, and adulthood than specific risk factors quoted such as poverty, poor health care, and family problems.

For some, these protective factors are found in family, relatives, and neighbors. For others, it is through more formal institutions of school, religious institutions, and counselors that support is found.

Building resilience in educational, social service, recreational, and other programs for youth with disabilities requires system-centered strategies that:

- Are not bound by traditional agency roles;
- Focus on enhancing strengths in young people as much as reducing the risk caused by the chronic condition;
- See the youth as part of the solution (not just the focus of the problem);
- Start early in the child's life;
- Are intensive, continuous, and developmentally appropriate;

Getting Through Adolescence:
Turn to page 88

RESEARCHER

The material presented here is based on the paper, "Risk and Resilience: A Model for Adolescent Health Interventions" (in press) written by Robert Wm. Blum, M.D., Ph.D. Dr. Blum is Professor & Director, Division of General Pediatrics & Adolescent Health, and Director of the National Center for Youth with Disabilities and the Center for Children with Chronic Illness and Disability at the University of Minnesota.

BEST COPY AVAILABLE

- Have staff who are collaborative, interdisciplinary, and not "overly professionalized";
- Do "what it takes" to be successful; and
- Value young people.

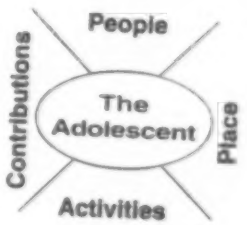
The key elements for resiliency-based programming can be summarized in the PCAP—"People, Contributions, Activities & Place" model below:

Resilient programs include:

People, especially an adult who cares, who is connected along with a network of adults who are involved in the life of the adolescent.

Contributions, especially the opportunity for the youth to contribute to family, neighborhood, community, youth involvement.

Activities through the school and community that develop a sense of connection/belonging.



A place for youth to congregate, to recreate with adult supervision, to develop friendships.

This PCAP model builds upon developing life skills while acknowledging the need for opportunities for involvement in school, family and community.

The Four C's of Resilience-Based Programs

Programs designed to promote resilience in children and youth with chronic illness or disabilities develop:

Competence: To improve the quality of the young person's life; to promote literacy and employability; to increase interpersonal, vocational and academic skills; to develop a sense of being able to contribute to his or her community.

Connection: Of youth to others through caring relationships and mentoring, tutoring, leadership and community service.

Character: Through values that give meaning and direction to youth such as individual responsibility, honesty, community service, responsible decision-making and integrity in relationships.

Confidence: To give hope, self-esteem, and a sense of success in setting and meeting goals.

The Center for Children with Chronic Illness and Disability is a research and training center dedicated to the study and promotion of the psychological and social well-being of children with chronic conditions and their families.

The National Center for Youth with Disabilities has the mission of improving the health and social functioning of youth with disabilities through technical assistance and consultation, disseminating information, and increasing services between the health care system and others. For more information call: 612-626-3042 or 612-626-2825, or e-mail: c3id@maroon.tc.umn.edu ncyd@maroon.tc.umn.edu

Youth with Disabilities & Health Care in the 1990's

The National Center for Youth with Disabilities has just published a new bibliography, "Children and Youth with Disabilities in a Changing Health Care Environment," as part of its *CYDLINE Reviews* series.

This publication provides an overview of many of the issues for children and adolescents as well as abstracts of resources for those who have use for information about health care reform issues and managed care.

Many states are attempting to control their costs by enrolling Medicaid recipients in managed care programs. They wonder if the often complex health care requirements of persons with chronic or disabling conditions will be met by managed care organizations. Many fear referrals could be limited, especially when providers emphasize primary care. Still others see the opportunity for managed care organization to provide better service coordination and continuity of care for youth with disabilities.

For information, contact: Elizabeth Latts, National Center for Youth with Disabilities, Box 721 UMHC, 420 Delaware St. S.E., Minneapolis, MN 55455, or call 612/626-2825 (voice).

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http://www.babyjogger.com/

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Circle #61

THE FAMILY EDUCATION NETWORK PRESENTS...

"Inclusion: A Personal Story"

by Ellen Goldberg

Orah Raia, pictured with her son, Brian, 11, will be writing a new on-line column for the Family Education Network.

Inclusion—it's a decision faced by many parents of children with special needs. How do you know what is right for your child? And where can you turn for advice, a pat on the back or to commiserate with others? The Family Education Network (http://www.familyeducation.com), that's where.

Introducing Orah and Brian

Meet Orah Raia and her son, Brian. In Orah's new on-line column, "Inclusion: A Personal Story," she'll share the story of her family's decision to include Brian, who has fragile X syndrome, developmental delays, attention deficit hyperactivity (ADHD) and significant communication deficits. Brian began inclusion in first grade.

In Orah's opening column, she writes: "This column is all about change and the journey toward not only accepting your life as it is, but establishing new priorities and bringing forth change. I will share with you the journey my family and I have taken since our son Brian was born with a disability 11 years ago. More specifically, it will be about the journey toward his inclusion in a general education classroom in his hometown."

Orah plans to feature guest columnists—such as her daughter, some of Brian's teachers, and possibly some of Brian's classmates or their parents—who will share their thoughts and perspectives on how inclusion affects them, as well as ideas on how to make it work for your family.

When Brian was diagnosed, Orah began to volunteer for the Statewide Parent Advocacy Network (SPAN), the parent training and information center in New Jersey. Now, she works for SPAN and provides training to parents and professionals on the rights of people with disabilities. One of Orah's other responsibilities is working on a project known as "All Children Belong," in collaboration with the National Parent Network on Disabilities. "All Children Belong" focuses on bringing the most up-to-date information on inclusion to 43 other parent training and information centers in the United States.

Our next columnist may be you!

You will find Orah's column at the top of the Special Needs channel, linked to a discussion group where everyone is encouraged to express his or her own stories and thoughts about inclusion. From these comments, we will be inviting people to submit their own stories for possible use in a future column.

Other FEN news

You may have noticed that the Family Education Network (FEN) has a new uniform resource locator (URL), or on-line address. It was families.com; now it's www.familyeducation.com. Make sure to update that address in your bookmark files.

By the time you are reading this issue of EXCEPTIONAL PARENT, FEN will have celebrated its launch, in Washington, DC, with U.S. Secretary of Education Riley and lots of other friends. Make sure to check us out regularly to see the new content we're putting onto the service, and to let us know what you think. **EP**

Ellen Goldberg is a producer at the Family Education Network in Boston, Massachusetts.

Find out more about Forum '96!

Get detailed information on attending Exceptional Parent Live:

- Go to the Family Education Network at http://www.familyeducation.com;
- Click on the "Special Needs" section, located toward the bottom of the screen;
- Scroll down to the end of the screen and click on "Come to Forum '96!"

We hope to see you there in October!

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Your child's education is on the line.

http://www.familyeducation.com

It's time to take control. Log on to the Family Education Network on the World Wide Web. Our free online service helps thousands of members get the valuable information they need – from educational resources, child development, and college planning to legislation that impacts families. No idle chat, no wasted time; just quick, concise answers to your questions.

Join the Family Education Network community. It's the best way to keep your children's education in line with the future.

For seven years we've been the credible, trusted resource for parents concerned with the education of their families. Now you, too, can enjoy the benefits of membership. Prepare your child for a competitive future. Receive discounts on award-winning educational products. Make your voice heard.

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Circle #89

Durable Medical Equipment

by Richard Epstein

I've received a number of letters from parents whose claims for durable medical equipment (including power wheelchairs, bath seats and other equipment) have been denied. All these cases seem to involve two major issues—first, the need to make sure the item is on the insurance company's list of "medically necessary equipment" and, second, the need to meet the company's test of "medical necessity."

In cases where a claim has been denied, the first step is to make sure the item is on the insurance company's list of "medically necessary equipment." If the item is not on the insurer's list, they won't pay for it.

For example, when I first began to use a power wheelchair, I anticipated some difficulty obtaining reimbursement from my insurance company. After all, power wheelchairs are expensive. Interestingly, the claim was approved without any problem. A year later, however, I bought new batteries for the chair and filed a claim for reimbursement. Although the batteries were only $200, both the initial claim and my subsequent appeal were rejected.

The problem was simple: Although the insurance company considered power wheelchairs "medically necessary equipment," wheelchair batteries were not in that category. Fortunately, the solution was also quite simple. I wrote to a supervisor at the company requesting that wheelchair batteries be placed on the list of "medically necessary equipment." I waited a month, and then filed another claim appeal. A few weeks later, I received a check.

The easiest way to determine if a specific type of medical equipment is on your insurer's list of "medically necessary equipment" is to talk with a supervisor at the insurance company. If the item is *not* on the list, write and ask that it be added. Then, wait a few weeks and file a claim appeal.

If the item *is* on the list, you move on to step two—demonstrating "medical necessity" through documentation. At the very least, this must include a letter from a doctor specifying your child's diagnosis and his or her need for the equipment.

Although the insurance company may already have detailed records of your child's medical history, this information needs to be specified again. Insurance companies deal with thousands of claims. The person processing your claim may not be fully aware of your child's diagnosis or medical history.

In addition, the doctor's letter needs to explain in detail why a particular piece of medical equipment is needed, and how that equipment relates to the child's medical condition. If the claim is for a power wheelchair, for example, the letter may specify that the child cannot walk and does not have the upper body strength to operate a manual wheelchair.

If your child needs a specific *type* of chair, that information should be included in the doctor's letter also (along with a list of any essential wheelchair accessories). It's also important to include letters from your child's physical or occupational therapists and an estimate from a medical equipment dealer.

When you've obtained these letters, attach them to your claim appeal and file it with the insurance company. If the insurer has the item on its list of "medically necessary equipment," and the test of "medical necessity" is met through appropriate documentation, your claim is likely to be paid.

But, just in case, take notes on the phone calls you make in regard to the claim. Include the names of insurance company representatives to whom you speak, the dates of these conversations and a brief summary of what is said. Make copies of all letters, explanation of benefits statements and other related materials.

If the claim appeal is unsuccessful, you have several options. First, you can discuss the situation with your local Protection and Advocacy Office (contact the National Legal Aid and Defense Association: 202/452-0620, voice; 202/872-1031, fax) or with a private attorney to determine additional legal steps, if any, that should be considered. Your records and notes may help in that discussion.

Second, funds to pay for medical equipment not covered by health insurance may be available from community service organizations, the local public school system or from a private foundation such as the Disabled Children's Relief Fund (402 Pennsylvania Ave., Freeport, NY 11520; 516/377-1605, voice; 516/377-3978, fax).

Finally, if you end up needing to purchase the equipment on your own, you might want to consider less expensive, used equipment. My May 1996 column, "Equipment Exchange Programs," details the work various state "Tech Act" programs have done in making used equipment available. **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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Directory of Schools & Residences

CALIFORNIA

Blind Children's Learning Center
18542-B Vanderlip
Santa Ana, CA 92705
(714) 573-8888 Fax: (714) 573-4944

The Children's Center of Riverside
7177 Potomac Street
Riverside, CA 92504-3933
(909) 784-0020 Fax: (909) 784-7062
Infant and preschool intervention program of education and therapy, classroom placement, home teaching, parent education and counseling.

COLORADO

Breckenridge Outdoor Education Center
PO Box 697
Breckenridge, CO 80424
(970) 453-6422 Fax: (970) 453-4676
Adaptive ski & year-round wilderness programs for kids of all abilities based in the beautiful mountains of Colorado (800) 383-BOEC

Excelsior Youth Center
15001 E. Oxford
Aurora, CO 80014
(303) 693-1550 x239 Fax:(303) 693-8309
170 bed treatment center and school for emotionally and behaviorally disturbed adolescent girls.

Laradon
5100 Lincoln Street
Denver, CO 80216
(303) 296-2400 Fax:(303) 296-0737
Early intervention and NAEYC accredited Preschool age 0-5; Community Adolescent Transition Center age 12-21. Comprehensive services to adults with developmental disabilities in community settings. Call for more info and a catalog of services.

CONNECTICUT

CIB/Oak Hill School
120 Holcomb Street
Hartford, CT 06112
(860) 242-2274 Fax:(860) 242-3103
Our community based education andresidential programs provide students with multiple disabilities every opportunity to achieve.
SEE OUR AD ON PAGE 75

FLORIDA

The Duvall Home
3395 Grand Avenue, PO Box 220036
Glenwood, FL 32722
(800) 358-0450 Fax:(904) 734-5504

GEORGIA

Agape Village
3711 Agape Village Road
Macon, GA 31210-4098
(912) 471-3700 Fax: (912) 471-3729
SEE OUR AD ON PAGE 69

Annandale Village
3500 Annandale Lane
Suwanee, GA 30174
(770) 945-8381 Fax: (770) 945-8693

IDAHO

Glacier Mountain Academy
4103 Loop Road, Cocolalla, ID 83813
(800) 675-4765 Fax:(208) 265-8766
Troubled youth with special needs
SEE OUR AD ON PAGE 97

INDIANA

Tradewinds Rehabilitation Center
5901 W 7th Avenue/PO Box 6308
Gary, IN 46406
(219) 949-4000 Fax: (219) 944-8134

IOWA

Easter Seal Career Center
2920 30th Street
Des Moines, IA 50310
(515) 274-1529 Fax: (515) 274-6434

KANSAS

Heartspring
2400 Jardine Drive
Wichita, KS 67219-4699
(316) 262-8271 Fax: (316) 262-0170
We serve children ages 5-21 with multiple disabilities in education, life skills, communication, and behavior management.
http://www.heartspring.org/heartspring
SEE OUR AD ON PAGE 6

Lakemary Center
100 Lakemary Drive
Paola, KS 66071
(913) 294-4361 Fax:(913) 294-4910

KENTUCKY

Kentucky School for the Deaf
PO Box 27
Danville, KY 40423-0027
(606) 239-7017 Voice/TTY
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Stewart Home School
4200 Lawrenceberg Road
Frankfort, KY 40601
(502) 227-4821 Fax: (502) 227-3013
SEE OUR AD ON PAGE 81

MAINE

Bancroft
Lighthouse Road
Owl's Head, ME 04854
(207) 594-7261 Fax: (207) 596-7662
Programs for people with developmental disabilities/ brain injuries. See Bancroft in New Jersey section.
SEE OUR AD ON PAGE 105

continued on page 94

The National Association of Private Schools for Exceptional Children

Founded in 1971, NAPSEC is dedicated to promoting excellence in private special educational settings for exceptional children.

- ***Nationwide Membership:*** Represents over 200 schools nationally, and over 600 at the state level through its Council of Affiliated State Associations, that provide special education to both privately and publicly placed children.
- ***Free Referral Service:*** Offered to parents and professionals who are looking for an appropriate private special education placement for their child or client.
- ***National Representation:*** Advocates for the rights of exceptional children and their families.

For referral or membership information please contact:

NAPSEC

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Woodstock, NY 12498
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LaCrosse, WI 54601
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Directory of Schools & Residences

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Benedictine School for Exceptional Children
14299 Benedictine Lane
Ridgley, MD 21660
(410) 634-2292 Fax:(410) 634-2640
The Benedictine Program has been nationally recognized for its pioneering approach to special education. It encompasses a three step process toward independence:The Benedictine School,The Habilitation/Training Center, The Open Community Program.

MASSACHUSETTES

Berkshire Meadows
249 N. Plain Road
Housatonic, MA 02136
(413) 528-2523 Fax: (413) 528-0293
For children and adults who have severe neurodevelopmental disabilities and complex medical problems. Private, non-profit residential setting in the Berkshires, offering a comprehensive approach to each individual's well being with integrated educational, medical and rehabilitative services.
SEE OUR AD ON PAGE 37

Boston Higashi School
800 North Main Street
Randolph, MA 02368
(617) 961-0800 Fax:(617) 961-0888

Castle School, Inc.
298 Harvard Street
Cambridge, MA 02139
(617) 354-5410 Fax:(617) 661-2549
Small therapeutic residential/day school for emotionally disturbed adolescents 13-18 year round, community-based, MA SPED-approved.

Eagleton School
Great Barrington, MA 01230
(413) 528-4385 Fax: (413) 528-6377
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Evergreen Center
345 Fortune Boulevard
Milford, MA 01757
(508) 478-2631 Fax: (508) 634-3251
SEE OUR AD ON PAGE 24

Green Meadows Community Services
Deerfield Avenue
Shelburne Falls, MA 01370
(413) 625-0281

IDDI, Crystal Springs School
38 Narrows Road
Assonet, MA 02702-0372
(508) 644-3101/451
Fax: (508) 644-3101/372
Licensed residential education and treatment programs for profoundly challenged children and young adults. 24 hour nursing
SEE OUR AD ON PAGE 97

Language and Cognitive
Development Center
11 Wyman Street/PO Box 270
Boston (JP), MA 02130
(800) 218-6282 Fax:(617) 522-9631

Kennedy Day School
30 Warren Street
Boston, MA 02135-3680
(617) 254-3800 Fax:(617) 254-6842

League School of Boston
225 Nevada Street
Newtonville, MA 02160
(617) 964-3260 Fax:(617) 964-3264
30 years of educating children with autism spectrum disorders. Day, residential and farmstead programs are available.
SEE OUR AD ON PAGE 65

The New England Center for Autism
33 Turnpike Road
Southboro, MA 01772
(508) 481-1015 Fax:(508) 485-3421
Day/residential school for children with develop. Disabilities, behavior disorders age 3-22. Integrated preschool, inclusion services, staff intensive program, functional activity based curriculum, supported employment in modern school and group homes.
SEE OUR AD ON PAGE 11

New England Villages
664 School Street
Pembroke, MA 02359
(617) 293-5461 Fax:(617) 294-8385
SEE OUR AD ON PAGE 34

Protestant Guild Learning Center
411 Waverly Oaks Road
Waltham, MA 02154
(617) 893-6000
Children and young adults with MR, autism, communication disorders, challenging behaviors, developmental disabilities. 12 mo. day/residential.

St. Coletta's of Massachusetts
400 Washington Street
Hanover, MA 02339
(617) 826-6371 Fax:(617) 826-6474
SEE AD ON PAGE 104

Willie Ross School for the Deaf
32 Norway Street
Longmeadow, MA 01106
V/TDD (413) 567-0374
Fax:(413) 567-8808
A total communication school dedicated to the education of deaf and hard of hearing students using an immersion/inclusion approach.

MINNESOTA

Lakeview Residential Program & School
2011 Nobles Street
Worthington, MN 56187
(507) 372-2983 Fax:(507) 372-2980

MISSOURI

The Miriam School
501 Bacon Avenue
St. Louis, MO 63119-1512
(314) 968-5225 Fax:(314) 962-0482
Day program serving children ages 4-12 with multiple learning disabilities. On-site therapies. Student/teacher 10/1. Summer program.

NEBRASKA

Bethphage Mission, Inc.
Lind Center, Suite A
4980 South 118th Street
Omaha, NE 68137-2220
(402) 896-3884 Fax:(402) 896-8751
Provides a variety of services to over 1600 children and adults with developmental disabilities through

programs in 16 states, Great Britain and Latvia. Bethphage - Where potential comes to life!

Meyer Rehabilitation Institute
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continued on page 96

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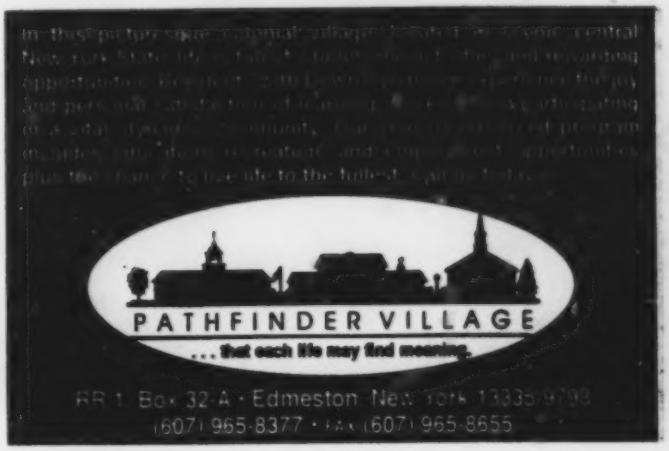

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•Future for Adult Services•Research and Development•

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Jerome Kagan, Ph.D., Harvard University;
Bernard Rimland, Ph.D., Autism Research Institute;
Diane D. Twachtman, Ph.D. C.C.C./SLP, Autism & Developmental Disabilities Consultation Center

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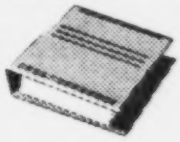

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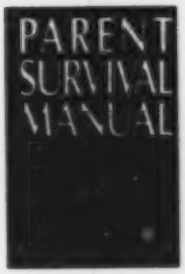
MEDIA

Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders

edited by Eric Schopler

REVIEWED BY TEDDI SOBIN



PARENT SURVIVAL MANUAL: A GUIDE TO CRISIS RESOLUTION IN AUTISM AND RELATED DEVELOPMENTAL DISORDERS, edited by Eric Schopler, is available through Exceptional Parent Library, (800) 535-1910; $29.95; Item No. PP1490D.

I have often suspected that parents require more observational skills than scientists and better creative problem-solving skills than high-level executives. And what is true for parenthood in general is even more true when it comes to parenting a child with special needs. No one told me that; I had to find out for myself. I was happy to find these lessons validated by the authors of *Parent Survival Manual: A Guide to Crisis Resolution in Autism and Related Developmental Disorders.*

This book is really more about problem-solving than crisis resolution. Most of the situations it deals with are not really crises, but troublesome, everyday challenges common to children with autism, intellectual disabilities or developmental delays—issues like communication, toilet-training or aggression. The book is actually a compilation of parent anecdotes about how they approached and solved those challenges. The anecdotes are organized and analyzed by professional behavior therapists. Sometimes it seemed as if the parents came by their solutions a little too easily, rather than flailing about for weeks like I do, but that may well be a result of the way their narratives were edited. Nonetheless, their stories were empowering.

I liked that the book dealt with very practical problems. A few years ago, when I was attempting to toilet-train my son, I could find very little information on useful techniques or approaches. I felt like I was groping in the dark. I thought some expert somewhere would have the answer, but in the final analysis, the experts were a waste of money. One day, everything just fell into place—the right time, the right motivation and the right tools—and the challenge was met. (My son was eight years old at that point.) I wish someone had told me just to trust myself and my son.

The parents sharing their stories in this book suggest surprising solutions to many problems, but, more importantly, they offer reassurance that parents can find the answers to their own parenting problems through observation, analysis and creative experimentation. The explanations surrounding the parent stories are written by therapists in "therapese"—professional therapy jargon—but I survived those parts of the book.

The book also includes a useful chapter, specific to the needs of parents of children with autism, about creating support groups and locating resources. However, much of the book will also be useful to parents of children with other developmental disorders, and I would recommend it to all parents who wonder how they can solve the day-to-day challenges they confront.

Theodora (Teddi) Sobin and her husband, Anthony, own an art gallery in Santa Fe, New Mexico, and parent two spirited children. Their oldest child, Nicholas, 9, was born with a heart defect and has speech and gross motor delays. Teddi is a graduate of Partners in Policymaking and is an "Adobe volunteer," assisting other parents with IEP concerns.

Equal Partners: African American Fathers and Systems of Health Care

Video & Discussion and Resource Guide

REVIEWED BY STANLEY D. KLEIN

James May and the National Fathers' Network have had a great impact on the lives of many people. *Equal Partners*, a new video produced with funding from the Department of Health and Human Services, Health Resources and Services Administration (HRSA) and the Child Health Bureau, continues this work by depicting the unique challenges African American fathers confront in working with health care delivery systems, investigating ways those systems can include African American fathers as "equal partners," and portraying African American men as capable, nurturing and involved in the care of their families.

I wish every parent could see this extraordinary video. It should also be required viewing for every political leader. It vividly demonstrates that men have feelings, that men can cry and, most of all, that African American men can be effective advocates for their children.

The *Discussion and Resource Guide* is also well-prepared. Its assessment tools can help health care programs and other organizations examine their own commitment to diversity.

This video has the potential to move people who may be narrow-minded about the role of fathers, fathers of color and the realities of health care for children with disabilities. Don't miss it!

EQUAL PARTNERS (25-minute VHS video and 90-page DISCUSSION AND RESOURCE GUIDE) is available from National Fathers' Network, Kindering Center, 16120 NE 8th St., Bellevue, WA 98008-3937; $55 (U.S.). Send check or money order payable to "National Fathers' Network." No rentals or previews.

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Circle #294

MOON WALKER

The Moon Walker is an advanced walker and walker training aid that can grow with the user. Designed for both indoor and outdoor use, the walker features a folding frame, padded hand grips and a removable, height-adjustable handle bar. For beginning walkers, the Moon Walker offers locked front casters and anti-reverse rear-wheel locks. As the child progresses, the front caster locks can be removed for easy turning and greater maneuverability. For even more advanced users, the rear anti-reverse wheel locks can also be swiveled up and out of the way to permit full forward and reverse motion.

Ortho-Kinetics, Waukesha, WI 53187

Circle #295

MOVIN'SIT JR.

The Movin'Sit Jr. is an inflatable vinyl seat cushion designed to promote endurance of the postural muscles by promoting active sitting. The 10" x 10" cushion encourages proper posture in any chair and can also be used in an automobile.

Ball Dynamics International, Denver, CO 80202

Circle #296

FLEXSEAT

The Flexseat is a polyurethane-foam wheelchair cushion designed to adjust to the user's shape by flexing rather than compressing. The flexing provides pressure distribution while avoiding localized pressure areas. This anatomically-shaped cushion features the FLOLITE II fluid padding system, a deep contour, adjustable rear width and nylon-and-Spandura stretch fabric cover. The Flexseat is available in six sizes to fit both children and adults.

Flofit Medical, Boulder, CO 80301

Circle #297

Q'STRAINT Q-5001-T

The Q'STRAINT Q-5001-T is a complete wheelchair-and-occupant restraint system for use in vans and buses. The system features heavy-duty floor-mounted aluminum "L" tracks (with or without flange), wheelchair tie-down straps and occupant seat-and-shoulder belts.

Q'STRAINT, Orchard Park, NY 14127

Circle #298

IMAGINATION EXPRESS DESTINATION: TIME TRIP, USA

Time Trip, USA, the latest addition to the Imagination Express Series, encourages interactive learning, promotes language development and improves communication, reading and writing skills. Among the available characters is a boy in a three-wheeled sports wheelchair. Font size and contrast can be customized for children with low vision. The CD-ROM-based program works on both Macintosh and Windows platforms.

Edmark, Redmond, WA 98073-9721

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT*'s "Free Product & Information Card." Readers can circle a number on this issue's card to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

875

PRODUCT SHOWCASE

Welcome to our Product Showcase, a special new service for Exceptional Parent readers. You can shop for the quality products and services shown here right from the convenience of your own home, or request more information from Product Showcase advertisers simply by circling the appropriate numbers on the postage-paid reader service card bound in this issue. The information you request will soon be delivered directly to your home.

AFB PRESS

The ***Hand in Hand*** series provides the resources needed to help students with visual and hearing impairments develop communication and mobility skills. These four books plus a video can be used separately or together. For more information and a free catalog from AFB Press (American Foundation for the Blind) call: **800-232-3044.**

Circle #1

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Circle #2

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Circle #3

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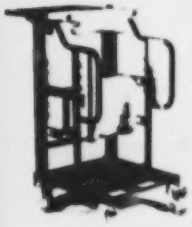
Circle #4

STAND-AID, JR. FOR CHILDREN



Give your children the benefits of standing: Fits youngsters 32 to 42 inches and up to 150 pounds. Provides all the physical and psychological benefits of vertical standing. Stand-Aid, Jr. supports the chest, hips and knees while keeping the feet in a secured position. This portable unit is designed to grow with your child.

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Circle #49

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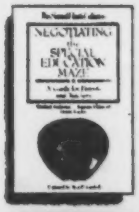

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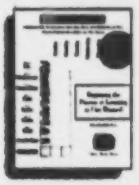

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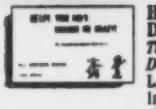

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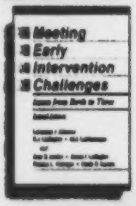

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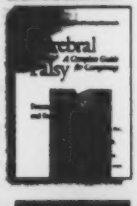

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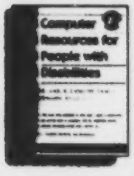

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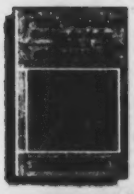

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Adventures With Surgery

by Odessa Black

Before my first surgery, I had to get a shot. I told the doctor, "Put the shot in my finger."

The doctor said, "No." He told me I had to get it in my arm.

I started to cry. I said, "Mommy, I don't want to have a shot!" I was angry.

"You have to," said Mommy.

A few weeks later, my mother said, "You're going home from the hospital!"

I couldn't move my head. I couldn't walk. I couldn't get my balance. But I was going home!

Odessa Black (front left) and her dad, Dan, mom, Lynne, and younger sister, Valerie, get into the holiday spirit outside their Manassas, Virginia, home.

My grandma was waiting for me at home. My sister, Valerie, was waiting, too. I got balloons. I showed my daddy the balloons. Daddy asked, "How are you doing, Odessa?"

"I'm happy to be home," I said.

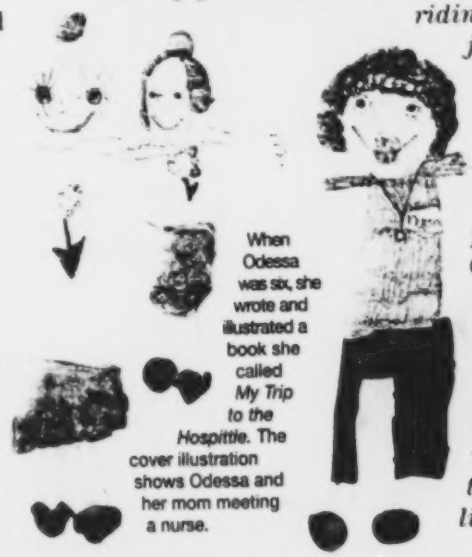
"We love you," said Valerie and Daddy and Grandma.

I couldn't do things like running or jumping, but it didn't matter. I was home, and I was happy.

Later, the doctors called. They said I had to have another surgery. They had to put a shunt inside my head. I was sleeping when they did it. I did not feel anything. It did not hurt.

Now I feel better. Every day I get stronger. I have to be careful not to fall, but I can play with my friends on the swings, the slide and the monkey bars.

Following shunt surgery, "I have to be careful not to fall," writes Odessa Black (right), "but I can still play with my friends on the monkey bars."



When Odessa was six, she wrote and illustrated a book she called *My Trip to the Hospittle*. The cover illustration shows Odessa and her mom meeting a nurse.

Odessa Black, 9, attends Bennett Elementary School in Manassas, Virginia, where she is in the fourth grade. Odessa lives in Manassas with her parents, Lynne and Dan, and her sister, Valerie, 6. Odessa was diagnosed with hydrocephalus at the age of six and has had two shunt revision surgeries to date. Odessa also has neurofibromatosis, type I, and attention deficit disorder.

She enjoys writing stories and letters, riding her bicycle, jumping rope, swimming, telling jokes, watching movies and participating in Girl Scout activities. When she grows up, Odessa plans to "be a nurse and take care of little babies."

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *EXCEPTIONAL PARENT,* 555 Kinderkamack Road, Oradell, NJ 07649-1517.

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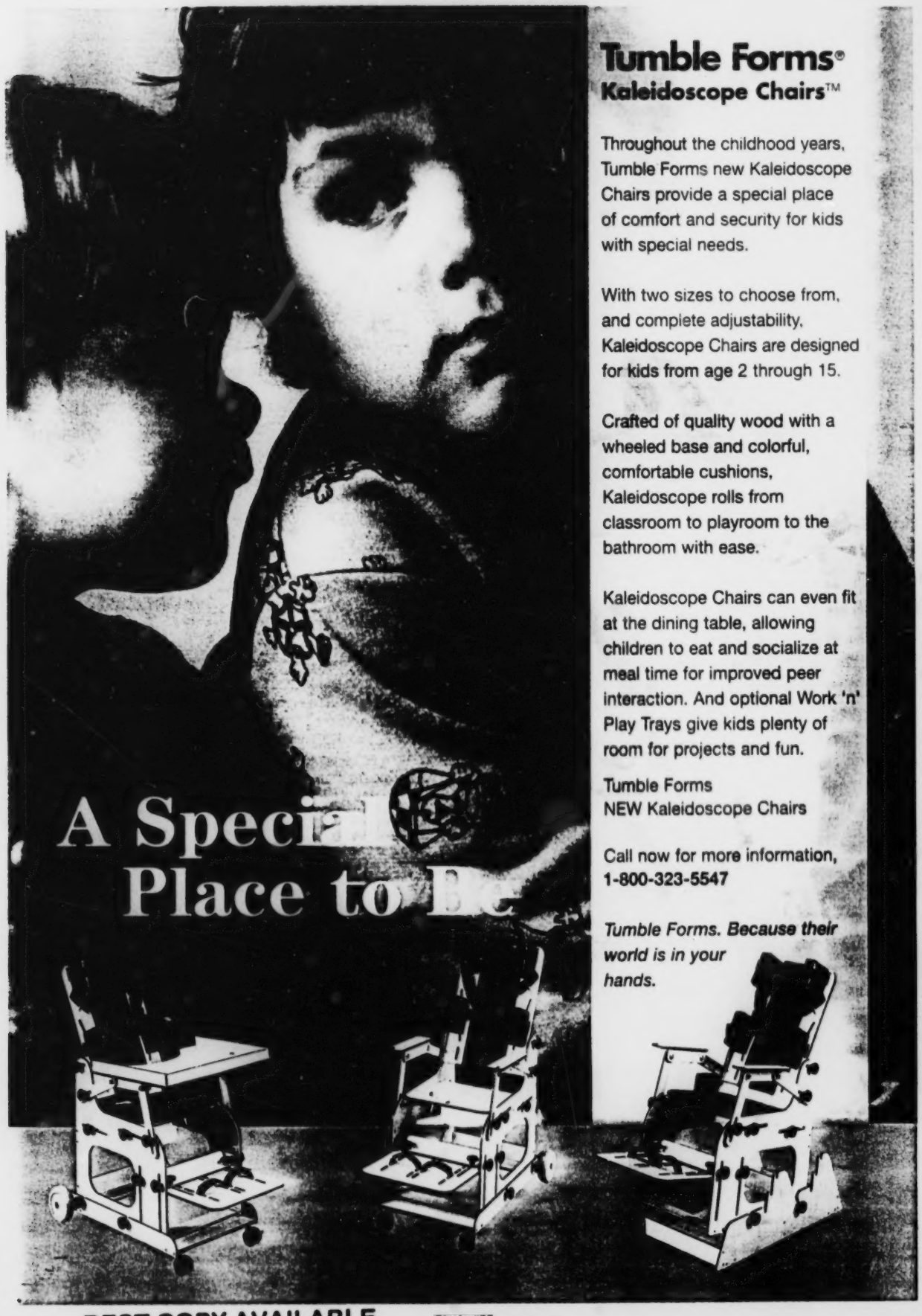

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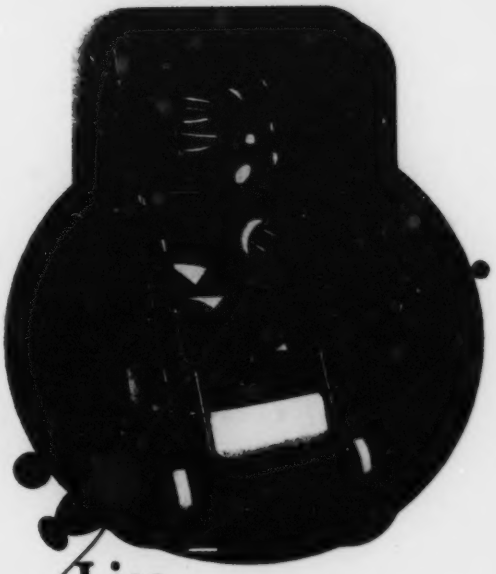

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EXCEPTIONAL PARENT
The Magazine for Families and Professionals
PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY
25th Anniversary 1971-1996
OCTOBER 1996 VOL. 26, ISSUE 10

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Above: Mary Tulin, 7, loves playing with nineteen-year old sister Claire, who has multiple disabilities. Their father, Roger Tulin, is the featured columnist in this month's Father's Voices on page 14.

Cover: Matthew De Rosa lets Mary Ann Cleary join in the fun as he plays with his Little People School Bus. Manufactured by Fisher Price, this toy is one of many featured in this month's special toy reviews on page 28. EXCEPTIONAL PARENT wishes to thank Fisher Price and its staff for their cooperation with this photo.

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EDITOR'S DESK

Demanding Answers

The June/July 1972 issue of EXCEPTIONAL PARENT contained an open letter to the platform committees of the Democratic and Republican parties:

STANLEY D. KLEIN, PH.D.

"...We urge you to pay careful attention to the needs of this significant group of Americans [children and adults with disabilities]. ...some of the major issues ...to be addressed:

- *Disabled children are frequently excluded from public educational programs.*
- *...attitudes deprive many disabled adults of the opportunity to be more self-sufficient vocationally.*
- *Environmental barriers...exclude disabled persons from...the rich diversity of American life...*
- *The need for long term care for some...places an extraordinary financial and emotional burden on their families.*
- *Large public residential 'warehouses'...shockingly inadequate...*
- *...desperate need for alternative community-based programs...including, in some cases, residential services..."*

In the next issue, we published each party's response. In this issue, as we have every four years since then, we are pleased to present statements by the leading candidates for President.

This year, because Presidential candidates know that federal laws mandate a publically-supported educational program for all children with disabilities (IDEA; the Individuals with Disabilities Act), as well as the end of environmental and other barriers (ADA; the Americans with Disabilities Act), we have asked "What should the role of the Federal government be in the enforcement of this legislation." We have also asked for opinions about early-intervention programs, adequate and affordable health care and the long-term needs of some children with disabilities.

We are pleased to publish the candidates' responses. At the same time, we urge all readers to ask the same tough questions of every candidate for public office. The remarkable changes that have taken place since 1972 have not come about because one political leader led the way. Each change has been the result of grass-roots efforts of parents, people with disabilities and other advocates, who have continued to speak out in order to educate our leaders, as well as their neighbors. And, every reader knows: There is still much more to do in every community.

The Role Model story illustrates the changing opportunities for people with disabilities as well as how much people with disabilities can offer to assist parents, professionals, and the younger generations of children with disabilities. We look forward to more input from individuals with disabilities.

Good News

Thanks to the untiring efforts of parents of children with mental illnesses, people with mental illnesses and many other advocates, health-insurance coverage provided by employers (with more than 50 workers) must include mental health coverage up to the same limits as for physical health.

As you receive this issue, Forum '96—EXCEPTIONAL PARENT's first exhibit show and educational conference—is underway in Anaheim, California. Among the many fine speakers, we are honored that Judy Heumann, our Assistant Secretary of Education, will be joining us.

We welcome Theresa Varnet, parent, advocate and a distinguished attorney to EXCEPTIONAL PARENT. Theresa will now be responding to readers questions about future planning in every other issue.

By now, many readers are visiting our Internet site at http://familyeducation.com. For those who have not done so as yet, please drop in and share your ideas and suggestions.

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For subscription and advertising information, see page 96.

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LETTERS

Thank you, EXCEPTIONAL PARENT!
My son, Neal, was born in 1978 with septo-optic dysplasia (a condition involving a visual impairment and pituitary disorder). Since Neal's birth, we have always been full of unanswered questions. We always wished we knew someone, anyone, with septo-optic dysplasia. All doctors could tell us was that it was rare. Eventually, we became resigned to the probability that we'd never run across another person with the condition.

But last year I heard about EXCEPTIONAL PARENT. I can't even begin to describe my feelings when I first heard that such a magazine existed. Euphoria! We had been living alone in the dark for so long; now there was a brilliant light at the end of the tunnel. I immediately subscribed.

This year, I received the 1996 Resource Guide which, to my amazement, listed my son's disorder. Although we are now living in Ireland, I immediately called the phone number listed. To my delight, the woman who answered had a child with septo-optic dysplasia who, coincidentally, had the same birthday as my son. We must have talked for an hour. She gave me the phone numbers of several other people in the States who had children with the same condition. I couldn't resist calling them, too.

As we plan a move back to the Chicago area, I look forward to expanding my relationships with these new friends. None of this would have been possible without your help. I wish all parents of children with disabilities could be made aware of your magazine as soon as they are made aware of their child's disability. I don't think any other service provides the kind of information and loving support EXCEPTIONAL PARENT has given me. We can't thank you enough.

C.B., County Donegal, Ireland

EDITOR'S NOTE: For more information on septo-optic dysplasia, contact FOCUS: For Our Children's Unique Sight, 2571 Pico Pl., San Diego, CA 92109; (619) 273-1473, voice/fax.

New Readers
My two-and-a-half-year-old son, Steven, has severe brain damage, no neck control and he doesn't laugh. Doctors have diagnosed him with a metabolic disorder called mitochondrial myopathy. He also has epilepsy.

A pen pal in the USA sent me a copy of EXCEPTIONAL PARENT. Your magazine is wonderful. I didn't know there was a magazine for parents of children with disabilities. Can I purchase the magazine in South Africa, or is it possible for me to subscribe?

E.O., Natal, South Africa

EDITOR'S NOTE: For information on international subscriptions, write to EXCEPTIONAL PARENT, P.O. Box 3000, Dept. EP, Denville, NJ 07834, or call (201) 634-6550.

continued on page 6

Correction
I wrote the article entitled "More Than a Health Care Provider," which appeared in the August 1996 issue. When I wrote the article, I indicated that when we met Ann Robertson, she managed therapy services at Grady Memorial Hospital in Atlanta, Georgia. However, she no longer works at Grady. Ann is currently the Facility Manager at Egleston Children's Rehabilitation Center at Century Center, in Atlanta, Georgia.

I would like to apologize both to Ann and Egleston for this error.

Egleston, you should be extremely proud to have Ann as part of your team.

Kim G.T. Savage, Douglasville, GA

Correction
August's Estate Planning column ("Supplemental Security Income") indicated that when determining SSI eligibility for a child under the age of 18 who lives at home with his or her parents, the Social Security Administration (SSA) considers only the child's income and assets. The article indicated that to be eligible for SSI, a child cannot have more than $2,000 in assets.

This information was incorrect. According to SSA, if a child is under 18 and lives at home, the parents' income and assets are also considered. For a family of four, the maximum income eligible for SSI is approximately $25,000; the maximum value of assets is $3,000. We apologize for the error.

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LETTERS

continued from page 5

■ I've just discovered my first copy of your magazine at our local Barnes and Noble Bookstore. It happens to be your 25th Anniversary issue (June 1996), which makes me wonder where you've been all this time! I can't believe I've never seen a copy before! The magazine is very informative, covering a wide range of disabilities and unique situations. I was especially intrigued by the ads for such useful products for children with special needs.

I have a grown daughter with Down syndrome, and I have been a foster parent and respite care provider for 15 years. In the last four years, we have adopted two siblings born with addictions and a multitude of other problems. They are doing great!

An article on how to find a good respite home and how to work cooperatively with a respite care provider would be beneficial to your readers. It would also be nice to see some articles on church activities geared toward people with disabilities and their families.

Keep up the good work!

M.S., Michigan

Correction:
The Pathways to Magic program, located in Chicago, IL, was featured in the August and September issues. The correct name is Pathways to Magic City Summer Camps. EXCEPTIONAL PARENT apologizes for this error.

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax). Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication but enables us to contact letter writers directly if necessary.

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Write to: *Readers Talk, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201)634-6598 (fax). A sampling of reader responses to this question will appear in a future issue.*

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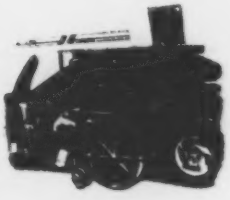

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To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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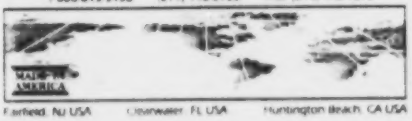

Fairfield, NJ USA Clearwater, FL USA Huntington Beach, CA USA

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Circle #64

SEARCH

Congenital Blindness

Our two-year-old son, Joseph, was born with x-linked congenital stationary night blindness and nystagmus accompanied with severe myopia.

When Joey was diagnosed at six months we were dumbfounded. I had a brother and maternal grandfather with some symptoms, but their conditions had never been named or genetically linked. Both are deceased, so linkage testing is impossible.

We also have a six-year-old daughter who may or may not be a carrier.

We are looking for another family who may be in the same situation.

J.F., New Jersey

Waterbeds

I read your article in the Respond section of the October 1995 Exceptional Parent about waterbeds for kids with cerebral palsy. I am very interested in getting one for my son.

He is fifteen-years old and has spastic quadriplegia cerebral palsy. He gets tight in the legs when he sleeps. His legs come up in an Indian style and he doesn't straighten them, so then they get cramped. He is starting to get a little scoliosis in his lower back. The bottom of his spine is bowing out, so I am trying all the things I can to help him!

Please send me information on the waterbeds as soon as possible because he's having surgery to lengthen his tendons behind the knees and I want him to be comfortable while he sleeps. Also, could you please tell me who the reliable waterbed dealers are?

N.A., Indiana

Narcolepsy and Absence Seizures

I am looking for a match for my six-year-old daughter's particular combination of diagnoses. She has narcolepsy (with cataplexy), and she has absence seizures (also called petit mal, etc.). This is a challenging combination of diagnoses because drugs commonly used with seizures cannot be used because they make the narcolepsy worse. For the last eighteen months we have had tremendous success using Felbatol to treat the seizures (although we have her CBC and liver function tested regularly). She is finally making developmental progress and is much more able to "follow along" with what's going on around her. Before starting the Felbatol, her developmental skills had stayed essentially the same—with no progress—for nearly three years. This was due to the extreme daytime sleepiness (narcolepsy) and the sixty to eighty absence seizures a day she was experiencing.

I would like to correspond with other families who are familiar with the overlapping diagnoses of narcolepsy and absence seizures. My daughter has severe mental retardation, is non-verbal (although she babbles intelligibly), is very social and "cute as a button." She is in a self-contained class at school, but "included" with other children in before and after school care and at summer camp at our YMCA.

She also has a clinical diagnosis of Prader-Willi Syndrome and I am already involved in our local chapter.

J.R., North Carolina

We need support

On December 6, 1995 our son, Jesse, was born. He was a month premature and a c-section was done since he was breech. He is a beautiful baby. We were so happy; we thought life could not have been more perfect.

At about four months of age we took him to see a pediatrician. We were concerned he did not seem to be focusing or looking at anything in particular. His development, which we had attributed to his being premature, also seemed slow. The pediatrician started talking about possible brain problems.

continued on page 10

EXCEPTIONAL PARENT
The Magazine for Families and Professionals
Parenting Your Child or Young Adult With a Disability

Editorial Mission

• To reach out to mothers and fathers of children and young adults with disabilities and special health care needs
• To empower parents and professionals by providing practical information and emotional support
• To appreciate that parents are the most important experts in the lives of their children
• To energize parents and professionals
• To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families

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Your baby looks normal... yet you know something is wrong.

Your child cries so softly and so rarely...seems to have little interest in eating or nursing...doesn't respond to people or objects...doesn't recover from colds... vomits frequently...is limp and always tired.

If your newborn or young child has some of these symptoms, he or she may have CARNITINE DEFICIENCY.

Testing is simple and inexpensive. Treatment is available. Delayed diagnosis has been linked to severe developmental disabilities such as mental retardation. Carnitine deficiency caused by metabolic disease can be fatal if untreated.

What is it? Carnitine is a naturally occurring substance that helps turn the food we eat into energy and protects the body from accumulating toxins that interfere with energy production. Babies and young children lack the enzyme to make their own supply of carnitine, but in most cases obtain the necessary supply from dairy products, breast milk, infant formula and red meats in their diet. Infants and children may be carnitine deficient due to a failure to transport carnitine into the cells. This is called primary carnitine deficiency. A deficiency resulting from poor dietary intake or a metabolic disease which depletes the body's stores of carnitine is called secondary carnitine deficiency.

What are the symptoms? Very poor muscle tone and coordination, chronic vomiting and fever, severe feeding problems, failure to thrive, little weight gain and/or weight loss, lethargy and unusual weakness, recurrent infections, flu-like symptoms, seizures or loss of seizure control, liver dysfunction and poor cardiac function.

What can you do? Consider the possibility that your child has a metabolic disorder if traditional treatments for a health problem don't seem to be working. Ask your pediatrician to check your child's carnitine plasma level. Be aware that carnitine deficiency is a symptom of metabolic disorders and further examination by a metabolic disease specialist is needed. Treatment for carnitine deficiency is simple and fast acting in acute cases. Contact Assistance for Babies and Children with Carnitine Deficiency for more information and support.

A parent-founded organization which serves as a source of support and guidance for the families of carnitine deficient children.

ASSISTANCE FOR BABIES AND CHILDREN WITH CARNITINE DEFICIENCY

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800-554-ABCD / 630-571-9608

Circle #83

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...ntinued from page 8

About four days after that, Jesse started having seizures. He crunches up, lifts his arms and his eyes looks like he is so afraid. Then he cries out after each one. Sometimes he has fifty or more seizures in a set. They were the most agonizing thing to watch. I felt so helpless.

We were sent to a children's hospital and were there for a month while they did tests and tried different medications. It was there we received the devastating diagnosis of symptomatic infantile spasms. Everything we read on his condition didn't give us much hope.

One of the drugs they put Jesse on was ACTH. It controlled the seizures for five days, but once he was started on the weaning process, the seizures started to come back.

We have since been for a follow-up visit which was even more devastating than the last one. Although all his tests have come back normal, his EEG is very abnormal. The doctors feel that Jesse's outlook is extremely poor.

He is six months old and unable to hold his head up. He still appears unable to see and doesn't respond to very much. They feel his seizures are a result of something very abnormal in his brain development and quite possibly will never be controlled. His outlook for development is not hopeful.

I really need support from a family who has gone through a similar tragedy. I love my little boy so much and my heart breaks at the thought of what his future holds. I hope you can help me.

T.S. & A.S., British Columbia

EDITOR'S NOTE: *Epilepsy Canada (1470 Peel St., Ste. 745, Montreal, PQ CAN H3A 1T1; telephone: (514) 845-7855) and Parent Care (9041 Colgate St., Indianapolis, IN 46268-1210; telephone: (317) 872-9913) may be helpful.*

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax Search or Respond, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax). For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812; (800) 999-NORD; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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Circle #56

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RESPOND

Breakaway Pants?

S.S. (July 1996) is an occupational therapist working in conjunction with a physical therapist on the independent catheterization of two girls with spina bifida. Both girls are in wheelchairs. The greatest difficulty these children have is pulling their pants up and down. There are additional complications involving the changing of sanitary pads and accompanying incidental bowel movements. She was seeking assistance from those who have overcome similar difficulties.

I, too, live in Illinois and have a somewhat similar need with my son. What has been a big help to me is the product called Securit-EZ. These are reusable briefs with disposable (adhesive) liners. The front of these briefs attach with velcro, and when open, swing all the way under. I purchased these briefs and liners from Shield Healthcare Center by calling 1-800-675-8847. They have an office in Elmhurst, Illinois, and ship by UPS. I get my orders in two days.

K.K., Illinois

Feeding and Toilet Skills

V.T. (August 1996) wrote in about her four-year-old daughter, Lisa, who has autism and severe mental retardation, along with hypertonia (muscle stiffness) and juvenile arthritis. Her therapist has described Lisa as "tactile defensive." V.T. was looking for suggestions from other parents about how to help Lisa acquire feeding and toilet skills, as well as advice about changing diapers in the "real world."

I do not know if I can be of service, but I too am an autistic, with other multiple handicaps of ataxia cerebral palsy, petit mal and motor seizures, partial fetal alcohol syndrome, moderate mental retardation, dyslexia and post traumatic stress disorder. I am thirty-nine years old. I had help writing this because I do not use the pronoun "I." But it is used for your response.

Let me tell you how I cope in the skills you need to know about. When I was two to eight years old, it was hard to toilet. I was very afraid of the whole process. However, I felt "safe" doing business facing the tank and flushing it myself. I had no clothes on to do it, and I sat like so to "feel" the flush and watch the elimination go away. I was fourteen years old before I felt safe to turn around, and eighteen before I stopped stripping my clothes. (By the way, don't use one-piece sunsuits or clothes.)

I also still use diapers at night and during the monthlys, because I cannot tell the difference of controls. My mother taught me at the age of eighteen years three months to use pads and diapers, but I taught myself to put on my own diapers after practicing

continued on page 12

Decisions. Decisions.

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Circle #57

continued from page 11

on a real-life anatomically correct baby doll.

Now about feeding: Does your daughter suck her thumb? I do still, and I also like bottles still. I am also tactile defensive. I do not like anything in the palm of my hands—not even the floor. I also prefer fingers to spoons—but it is easier to use a spoon with a big handle and a round bowl. I cannot drink from a cup, glass or plastic because I bite the edges too hard and I chew the paper ones because they contain wax in them. I also chew on styrofoam ones too. I have a problem with pica (craving for non-food substances), too. It is easier for me to drink from a trainer cup, trainer bottle or a sport bottle. I choke on straws.

I also lose my balance a lot and tire easy, too. I think it is because there is so much internal energy that can't get out. I lay down and rock, sometimes to sleep—but once recharged, I am OK. I also want to say that these skills are the hardest to learn of all, next to the 3R's. I am still learning to eat civil—but I backslide a lot because of a lot of stress. There are a lot of parts to learn in these skills.

C.C., Ohio

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860/242-2274, Ext. 851

Circle #58

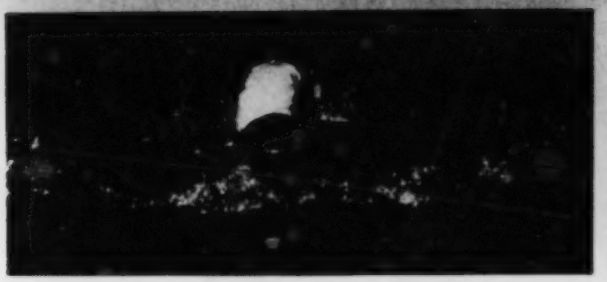
Dystonia

D.M., (February 1996) has a daughter who was originally diagnosed with cerebral palsy. However, she was rediagnosed with dystonia, a rare muscle tone disorder. She was looking for other parents who had experience with dystonia and its treatment.

I would somehow like to be put in contact with D.M., Illinois. My little boy also has been diagnosed with cerebral palsy (quadriplegia of the mixed type) at nine months of age. He is almost three and still has shown no form of brain damage. Unfortunately, we have to fight for any assistance, being in the military and living in Hawaii. The military doctors won't even give the dystonia label a chance. It is only a symptom, not a disorder.

Everyone says go out in the community for a second opinion. Unfortunately, I can only do this with military approval or I will have to pay for all of the medical bills. Our insurance won't cover any services unless we have military approval. My family cannot afford this along with all the therapies and medical-equipment expenses. I have contacted the Exceptional Family Member Program. There are no doctors here that know anything about dystonia. Still, it is so much easier to talk over these things with a parent who has been there. We all seem to be on one wavelength.

B.B., Hawaii



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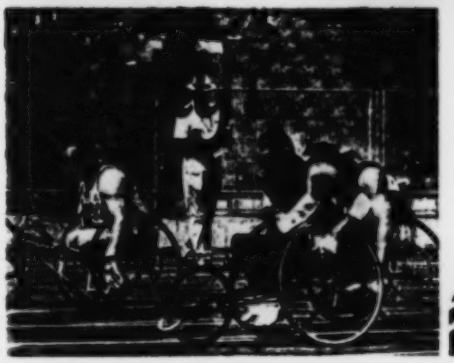

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Her Life, My Life

by Roger Tulin

I was almost 29 that spring when I held my wife's head from behind her pillow and watched as our first baby's head appeared, full of thick hair. She was quiet and, to my astonishment, her eyes, still and steady, stared right into mine.

As I held my new daughter against my shoulder and walked around the room, I felt peaceful and good. "You've got the jiggle already," a nurse said to me as I bounced ever so slightly up and down on the balls of my feet. "You can give her back now, Roger," she said. "You're going to have her for the next 18 years."

Last fall, the 18 years were up, but our Claire didn't go off to college. Since 1977, I've been the father of a child with multiple disabilities.

Claire, 3, and her mom, Marie, explore the beauty of autumn leaves. "Until we decided to have another child," writes Roger Tulin, "my wife and I made working with Claire the major focus of our lives."

Refusing to see

When Claire was an infant, we noticed that her body was loose and floppy. Benign congenital hypotonia, the doctors told us. It would improve, but she'd never be an olympic athlete. "Let me know when she takes her first steps and says her first words," the neurologist said.

Claire finally walked at age two, and for the first years, I refused to believe anything was wrong that couldn't be fixed. Even as she fell farther behind, I clung to the belief that maturation would prevail and that our girl might even write poetry some day. Meanwhile, Claire made tiny, incremental steps as one developmental milestone after another passed us by.

There was joy, along with pain, in being Claire's father. We went sledding together and she rode on my bike with me sitting behind. She loved walking, especially in the evening, and "night walks" became a special part of our lives, one that we still enjoy. I found within myself a capacity for patience and love I didn't know I had.

The enigma

By the time Claire was eight years old, I had begun to accept the truth of her mental retardation—it would never go away. But what, I kept asking myself, does "retarded" really mean anyway? I knew that somewhere behind all Claire's difficulties was a thoughtful and sensitive person struggling to break through, a whole human being with thoughts and feelings.

When Claire was 10 years old, I took her to make a final visit to my grandmother in a nursing home. As we began the long drive home afterwards, Claire startled me by asking, "Dad, does she do anything in there except wait for people to come visit?" Instantly, my dutiful complacency was pierced. My daughter, not I, felt real compassion.

A few hours later, we stopped at a rest area. I waited apprehensively, wondering if this time Claire would be able to find her way out of the women's room by herself. Between such extremes, I struggle to make sense of the enigma that is this child's life.

A painful turn

Much of Claire's painfully achieved progress was blown to pieces by the onset of temporal lobe epilepsy at the age of 11. As we searched for the right combination of anti-convulsants, we watched our daughter grapple with the cruel interaction of mental retardation and a seizure disorder. For months, she didn't smile; inexplicably, she began biting her skin and chewing her own hair. At 13, a combination of frustration and physiology brought on a full round of psychotic symptoms. Claire seemed to respond only to inner voices, and her spoken words became impossible to understand. She became impulsively aggressive toward us and her younger sisters.

Slowly, the whole family began to deal with the reality that we could no longer meet Claire's needs at home. I stubbornly resisted the inevitable, guilty, grieving and afraid to let go. "You can't live your life driven by guilt," my wife hammered away at me. "It isn't fair to you or us." In the fall of 1990, Claire began life at a residential school about an hour away from our home.

Suddenly, there seemed to be an enormous amount of time—especially time to spend with our two younger daughters. Too often, they had lost out in an impossible juggle of my time and energy, and they knew it. My wife and I began learning to live together without having to focus most of our attention on our first child. Still, in the first several weeks after Claire's move, I felt lost and empty. I'm still learning to make my way forward in this newfound freedom; so much of my life had taken its meaning from hers.

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Sharing a tender moment in the spring of 1996, May, 7, helps her older sister Claire, 19, play a game in their backyard.

Coming of age

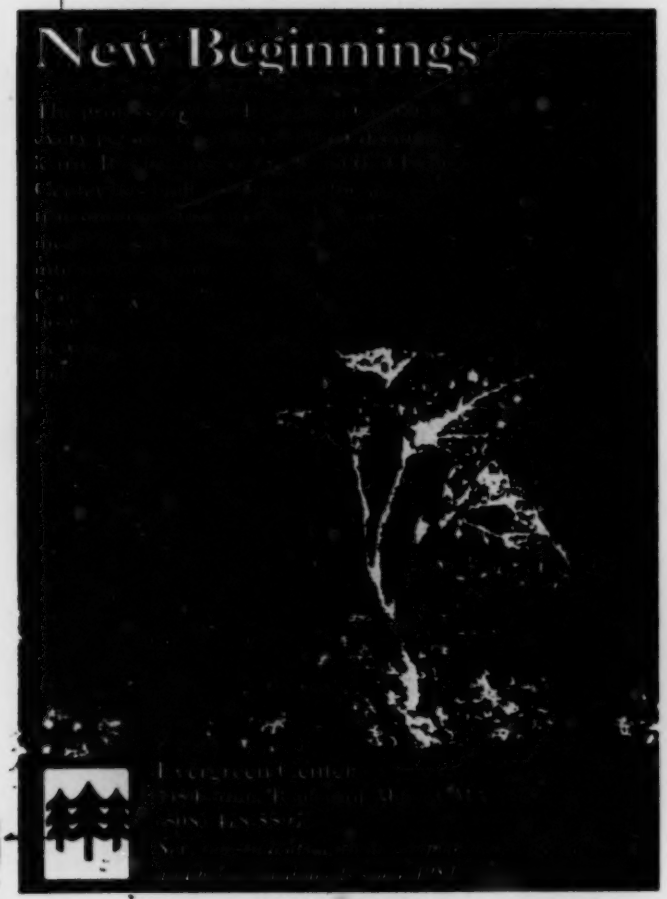
Claire is 19 now, a young woman with mental retardation. She lives in a group home only minutes away and visits home frequently. Her younger sisters show their love for her again; their resentment is in the past. Chronologically, Claire's childhood is over, and the only certainty is that she'll outlive her parents by thirty or forty years. Our greatest hope is that she can attain enough skills to work at a job someday.

In my life as Claire's father, I came of age as a man, saw myself in new ways and learned to do things I never imagined I could do. The hopes I held so long and so stubbornly for Claire have not become reality—and that grief is part of my life. But the things I learned from being her father are mine to nurture and keep. I try to share them now with the family that loves me. And I try to use them sometimes myself. **EP**

Roger Tulin lives with his wife, Marie, and his daughters, Gwen, 12, and May, 8, in an old farmhouse in Lexington, Massachusetts. His oldest daughter, Claire, 19, lives in a nearby group home. Roger has been a teacher, newspaper reporter, factory worker, roofer and carpenter, but for the last ten years, he has worked as a lead machinist in a mold repair shop. He enjoys working on his house, playing folk guitar and writing.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.



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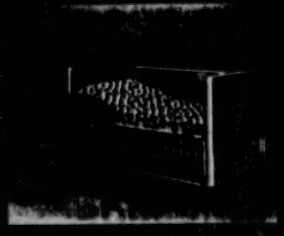

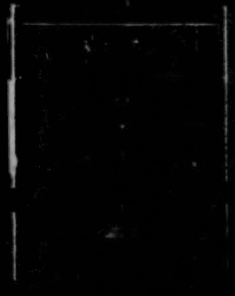

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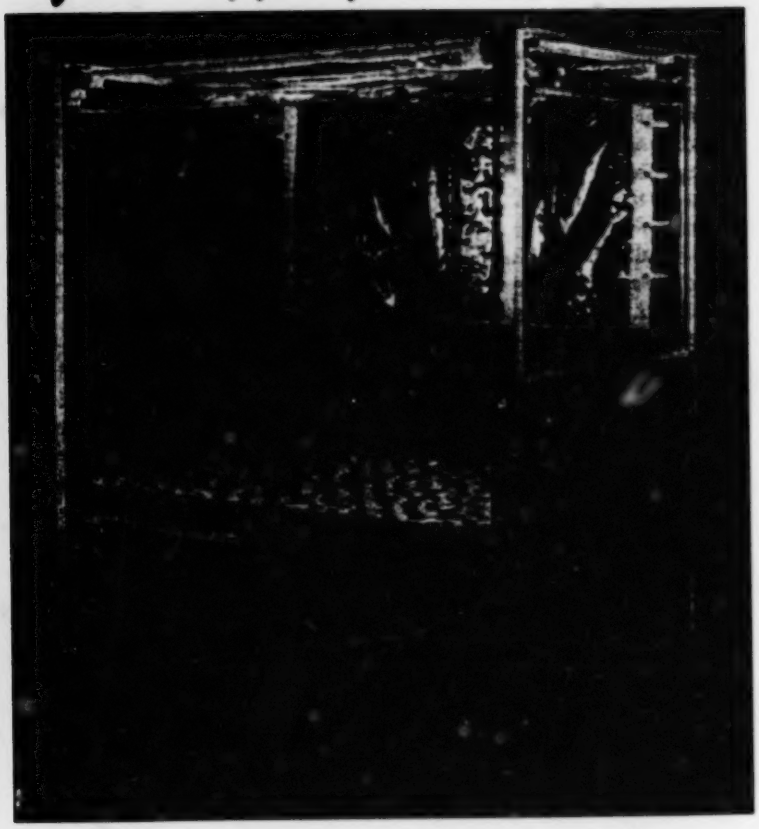

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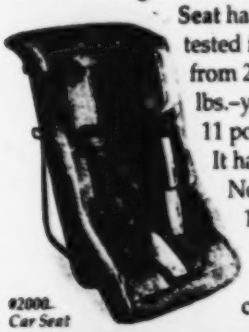

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Circle #68 902

FORD MOBILITIY MOTORING:
It Takes a Team

The Ford Motor Company Mobility Motoring Program wasn't the first. It may not have always been the biggest. But Mobility Motoring has made a positive difference for thousands of individuals and families with children who have physical disabilities with a team approach that provides a lot more than just cash!

Developed in 1992 with the cooperation of the Louisiana Tech Center for Rehabilitation Science and Biomedical Engineering, Ford Mobility Motoring promotes a team effort that includes the person with the disability, his or her family, the Ford or Lincoln-Mercury dealer, an assessment center and the adaptive-equipment installer. The objective of this team approach is to deliver a vehicle that's the right size, properly equipped and eligible for Ford Mobility Motoring assistance of up to $1,000. The key to keeping this process rolling along smoothly is the team at the Mobility Motoring Helpline at 1-800-952-2248 (TTY 1-800-833-0312).

Ford
MOBILITY MOTORING
PROGRAM

A Call to the Helpline Triggers an Avalanche of Useful Materials

Whether a vehicle conversion is intended for a driver with a disability or to transport a child or young adult with a disability, a caller to the Mobility Motoring Helpline receives a list of nearby assessment centers, a listing of local adaptive equipment installers and a videotape that introduces the viewer to real people whose adapted vehicle enhanced their lives with a feeling of freedom and independence. The Helpline package also includes a personalized processing-assistance claim form for the cost of adapting a vehicle up to a maximum of $1,000.

A Straight-Forward Process

The process is a caring one.

- **First, visit your dealer.** Get an idea of the Ford, Lincoln or Mercury vehicle you would like to have before you visit an assessment center or installer.
- **Let an assessment center help.** Driver assessment centers provide help in the selection of adaptive equipment that is right for the driver or passenger with a disability. The centers can then write a "prescription" for the required adaptive equipment. This prescription can also help assure that the equipment installed is eligible for Ford assistance. Many assessment centers offer adaptive-equipment training. All provide useful information about ways to meet exceptional-transportation needs.
- **Installers are a vital link.** Once an installer understands an adaptive-equipment customer's needs and the kind of vehicle in which it will be installed, he or she should be able to give you a written estimate before the job begins. An installer can also often supply helpful information about wheelchair lifts and personal mobility devices without the need to visit an assessment center.
- **Training is a must,** especially if the adaptive equipment is new to the user. Training include equipment installers, the assessment center's driver evaluator or a qualified driving instructor. Some states require special training before issuing a driver's license for vehicles adapted for drivers with physical disabilities.

A Cellular Phone and Roadside Assistance Add to the Value

For those who purchase or lease a new Ford, Lincoln or Mercury vehicle and have adaptive equipment installed, Ford also offers a complementary Ford Cellular Phone—handy for anyone who's on the road. This fully transportable phone does require a minimum 121-day new activation on the Ford Cellular System. While some individuals will not want the phone, since it does carry certain additional financial obligations, it's a very good match with the Ford Roadside Assistance Program that's part of the Ford Three Year/36,000-mile Bumper-to-Bumper limited warranty. During the entire warranty period, one simple call to an 800-number brings assistance, 24-hours-a-day, 365 day-a-year, for emergencies like towing, a tire change, out-of-gas fuel assistance, lock-out assistance and battery jump starts. Vehicles covered by the Lincoln Commitment, Mercury Commitment or Red Carpet Lease plans may have additional benefits which can be explained by your local Ford or Lincoln-Mercury dealer.

Ford Motor Company's caring team approach with Mobility Motoring underscores its original commitment to individuals with disabilities and families with children who live with a physical disability: In fact, for many thousands of Ford Motor Company customers, the freedom and independence enhanced by Mobility Motoring has meant that their lives can be easier and more exciting as well as more rewarding!

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

Move Forward With Mobility Motoring

Ford Motor Company understands everyone's pursuit for an active and independent lifestyle on the road. That's why the Ford Mobility Motoring Program provides comfort, value and assistance for persons with physical disabilities when purchasing or leasing a new vehicle:*

- **Up to $1,000 Cash Assistance** towards the installation of adaptive equipment on all Ford and Lincoln-Mercury vehicles.
- **24 Hour Roadside Assistance** for the duration of the bumper-to-bumper limited warranty.
- **A Complimentary Ford Cellular Phone** It's fully portable for use anywhere and all you take care of are the service and usage charges.
- **State Information Packets** We'll provide you with a list of qualified assessment centers, adaptive equipment installers and dealers, and potential sources for additional funding.
- **Plus, Ford Has It All Together**

Get Your Ford Mobility Motoring Information Kit Today!

Call 1-800-952-2248 (TTY users call 1-800-833-0312)

Ford Mobility Motoring ... Moving Forward With You

*Please see your Ford or Lincoln-Mercury Dealer for complete details about all of the Mobility Motoring benefits, or call 1-800-952-2248 (TTY: 1-800-833-0312).

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Circle #61

Familiar Faces

At six years old, **Brittany Guarino** of Weeki Wachee, Florida, has already traveled extensively throughout Europe, but her favorite place is still Disney World! Fully mainstreamed into her kindergarten class, Brittany is autistic and non-verbal. Her mother, Michelle, says she is "a very happy and bright little girl, and an exemplary student." Brittany also loves playing with her dog, Brina.

Two hundred miles can't keep these two apart! **Ted Dawson** (left), an 11-year-old from Buffalo, WY, loves getting together with 10-year-old friend **Jordan Yager** of Rivertown, WY. Although two mountain passes lay between them, Ted and Jordan, who both have Down syndrome, look forward to the time they can spend together. They love fishing and camping, playing soccer and singing rock-n-roll music!

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517 (Sorry, photos cannot be returned). On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

905

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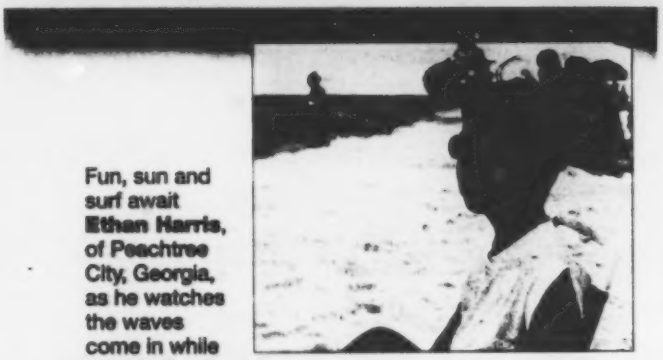

Fun, sun and surf await **Ethan Harris**, of Peachtree City, Georgia, as he watches the waves come in while vacationing in Florida. Ethan, 6, loves to play in the sand, read books and sing. According to his father, Nick, "He constantly keeps the family motivated and striving for success." Ethan's favorite pastime is watching Barney and putting on a stage show for mom, dad, sister Logan, 4, and brother Adam, 15. Ethan has Down syndrome.

Joey Ferens, of Bruck, New Jersey, shows off on the turtle sandbox his parents gave him for his second birthday. Joey loves playing with his sister, Gina, 6, and swimming with Dad. Joey was born with x-linked congenital stationary night blindness, nystagmus and severe myopia, but his parents say he is "a very active two-year-old and doesn't let his lack of vision stop him."

Four-and-a-half-year-old **Chuckie Magee** of Manheim, Pennsylvania, doesn't have to put on an act in front of the camera, "He's always as happy as this picture," says his mother, Beverly, adding that "God has blessed us with such a unique little guy!" Chuckie has a heart defect, mild mental retardation, seizure disorders, asthma, submucous cleft and other multiple problems, but can always be found with a big smile on his face.

Betsy will outgrow her toy before she outgrows this seat

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Circle #77

Paul Longmore, Ph.D., 50, is an associate professor of history at San Francisco State University (SFSU). Longmore, author of THE INVENTION OF GEORGE WASHINGTON *(1988, University of California Press), specializes in early American history. He has also written many scholarly articles on the history of people with disabilities.*

Longmore, who contracted polio at the age of seven, graduated from Occidental College and The Claremont Graduate School. At SFSU, he also serves as faculty advisor to the organization of students with disabilities. "Teaching gives me an opportunity to give back to my students what I received from my best teachers," he says. "My students with disabilities can talk to me about things they have never been able to discuss with anybody else."

The following was adapted from an interview between Longmore and EXCEPTIONAL PARENT *editorial intern Naomi Wernick.*

Paul Longmore

"Disability isn't just a set of obstacles to be overcome."

I got polio during one of the last epidemics, a year and a half before the Salk vaccine came out. I had flu-like symptoms one night. The next morning, I was trying to get dressed, but my left arm was paralyzed. I went into my mother's bedroom holding my left sock and said, "Mommy, my arm doesn't work. Could you put on my sock for me?" Instead of putting on the sock, she called the doctor. That afternoon, I was admitted to the hospital. I was there for five months and in a rehabilitation hospital for another nine months.

During that time, I saw very little of my family. Hospital rules prohibited visits from my younger sister. I saw her only once, when my dad brought her up the fire escape. They turned my iron lung around so I could see her standing outside the window, and I broke down crying. My parents came during visiting hours, but at the rehab hospital, that was just four hours a week. Every time they walked out the door, I thought I would never see them again.

Coping as best we could

We all coped with my illness the best way we could. I still have the notes my parents wrote me while I was in the hospital. The notes urged me to do exactly what I was told by the doctors and therapists. Rereading those notes, I can see how terribly frightened they were.

Most of the time, however, my parents didn't tell me what was going on. The worst instance of that occurred when I was almost 11. I overheard my mother whispering to my sister about a series of operations that were to be performed on my back. I rushed into the kitchen to confront her. She told me that the next day I was going to the hospital for a spinal fusion. I was going to be there for months, laid up at home for months longer, and in a body cast the whole time. I had great difficulty trusting my parents after that.

That surgery saved my life, but at the time, doctors didn't understand that it was a bad idea to fuse long segments of spine in a child that young. As I grew, it caused my spine to bow forward into my chest cavity, making it difficult to breathe. I began using a ventilator when I was in high school.

Advocacy and resistance

On the other hand, my mother could be my advocate—especially when it came to my rehabilitation. For instance, both my arms have been paralyzed ever since I got polio. I have usable muscles in my right shoulder and I can use my right hand. Therapists at the rehabilitation hospital wanted me to wear an orthopedic device called a feeder to support and allow me to use my left arm, which didn't work at all. At the end of the feeder was a prosthetic hook, which I could open and close through a wire running up my arm and down my left side to my foot. It didn't allow me to use that arm; worse, since I couldn't control the way my arm swung in the feeder, the hook would end up blocking my right hand, leaving me unable to use *either* hand.

I decided I wasn't going to use it anymore, and my mother agreed with me. The hospital staff said we were both "resistant." That's a label they put on people who don't comply with what professionals decide is best.

A similar situation occurred when I was in ninth grade and an occupational therapist decided to teach me how to dress myself. The pitch she used was, "You don't want your mother dressing you like a little baby, do you?" Any teenager would go for that line! So I tried dressing myself for two months. It was exhausting. Finally, I said, "This is a waste of time. I'm tired by the time I'm dressed, and I still have a full day of school ahead of me." My mother agreed it made more sense for her to help.

Rehabilitation goals often have nothing to do with health but with the cultural ideal of autonomy. Therapists rarely ask, "What's the smartest or most efficient way to do things?" Well, although they called us resistant, my mother and I made decisions based on efficiency.

Adolescent awakenings

In seventh grade, I took a woodworking class. The teacher, Mr. Jeldum, was a man who'd had polio and who walked with a very significant limp. I worked very hard in his class. I made all sorts of things. It took a lot of energy. Now I realize I wanted to please him because he was the only disabled adult I knew. Even though I wasn't consciously aware of it, he meant a lot to me. I needed an adult I could look at and say, "Wow, he's got a disability, and he's succeeded. People like him and respect him. He has a job. I could be like him."

About that time, I first became aware that I was confronting prejudice from adults. It took me a few years to label it "prejudice," but that's what it was, and I knew it.

First, adults didn't expect much of me. They praised me for doing ordinary things they wouldn't have even mentioned if I didn't have a disability.

Second, they wouldn't criticize me. Not that I wanted criticism, but I wanted honesty. Adults treated me like I was emotionally fragile. And I remember thinking, "I almost died, and you're treating me as though I'm fragile?"

I stopped trusting people's praise. It wasn't until I was in graduate school that I finally met somebody I trusted. That guy became my dissertation adviser. I trusted his praise because he also criticized my work.

Anyway, I became aware of this dishonesty and condescension, and by the time I was 14, I was coming home and saying, "So-and-so is prejudiced against me because of my disability."

I think my parents knew it was true but didn't know how to deal with it. They were not political people, so they didn't have any social or political context for my experience. They had no sense of things like civil rights. So, their reaction was, "No, it's not true. You're too negative."

But I knew I was right. I needed them to tell me, "It's true, Paul; there is a lot of prejudice. It's gonna be hard, but we're going to help you find ways to fight it. You won't be alone."

When I became a disability rights activist as an adult, my parents got kind of worried. I remember my mother saying, "You know, people used to talk about how cheerful you were. Now, you seem awfully angry."

And I said, "I've been angry for a long time. But now, I have a vehicle to express it."

Civil rights

Growing up, I thought that the way to achieve social legitimacy was to identify with people who weren't disabled. Even in college, I avoided the three other students with disabilities. And they avoided me.

At the same time, however, I was dealing with all these identity issues—questions about how to live my life, about romance and sex, about my future and about my place in the world. Although all college students deal with these issues, in my case, everything was complicated by my disability and the prejudice I knew I was confronting.

In fact, based on my own experiences and observations, I was developing a civil-rights consciousness. By the end of my college years, I was telling myself that there needed to be a civil rights movement of people with disabilities. I wasn't aware it had already begun.

Paul Longmore teaches a colonial history class at San Francisco State University. "Teaching gives me an opportunity to give back to my students what I received from teachers such as Mr. Jeldum and my Ph.D. adviser," he says.

PHOTOGRAPHY BY SUZANNE C. LEVINE

Once I began to talk to other people with disabilities and listen to their experiences, it transformed my life. I no longer felt alone. I realized that the only way to overcome prejudice and discrimination was by acting in solidarity with other people with disabilities. That's when I got involved with disability rights activism.

Graduate school

The California Department of Rehabilitation (CDR) refused to give me financial assistance for graduate school. A wealthy man I met paid my first year's tuition;

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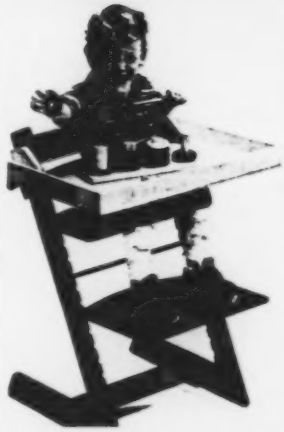
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Circle #41

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after that, I managed to pay for one course a year by saving money out of my monthly Supplemental Security Income (SSI) checks. But I never stopped looking for other kinds of assistance. I applied for conventional academic fellowships, but was turned down because, as they said, "Nobody is ever going to hire you as a teacher." I contacted a number of disability-related organizations, but they told me they didn't supply that kind of assistance. I even went on a television game show, Tic Tac Dough.

I worked on my Ph.D. for six years with no weapons to combat the discrimination I was facing or to force the school to provide me with reasonable accommodations. But in 1977, Section 504 of the Rehabilitation Act of 1973 took effect. It prohibited discrimination against people with disabilities in federally funded programs or activities. At that point, I went to my academic advisor and said, "Now the school has a legal obligation to help me."

After I pushed CDR, it, too, began to provide some tuition assistance and, more importantly, money to pay for transcription services. What a difference that made! All of a sudden, I became extraordinarily productive. All these years, I had been telling myself I was lazy—blaming myself for not living up to my potential. Once I got some assistance, I realized I wasn't lazy at all; I just hadn't had the means to do my work.

But even as my work started going better, I struggled with worries about the future. Because I was receiving SSI, I was eligible for health insurance through Medicaid and for in-home support services. Unfortunately, SSI regulations stated that if a recipient ever earned more than $300 a month for more than nine months, they would become forever ineligibile. I knew I could easily earn more than $300 a month, but I knew I couldn't earn enough to afford the ventilator or the in-home support services; and without those things, I wouldn't be able to live on my own.

I constantly asked myself, "Why am I struggling to get this Ph.D. when I'll never be able to take a job because I'll lose my government assistance?" Every semester, I came close to the point of quitting. Finally, in 1988, Congress changed the SSI regulations to permit people to get a job and still maintain eligibility for SSI for a time. This allowed me to search seriously for a teaching position for the first time.

Teaching and learning

I like being with students. I like communicating with students. Mostly, we discuss American history and how to think about history, but students also talk to me about their lives, seeking advice or encouragement. Sometimes, the immediate topic of conversation is their work in my class, but the real issue may be how they do their work and how they view themselves.

I teach a course on the history of people with disabilities. I said to myself, "You know, almost nobody's looked at the

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history of people with disabilities. And here I am, a historian ..." So, I had to do it.

I get a lot of students with disabilities in that class. It's the first time any of them has had an opportunity to study the disability experience in an intellectually serious way. And it's usually the first time that most of my students—with or without disabilities—have ever had a teacher with a disability.

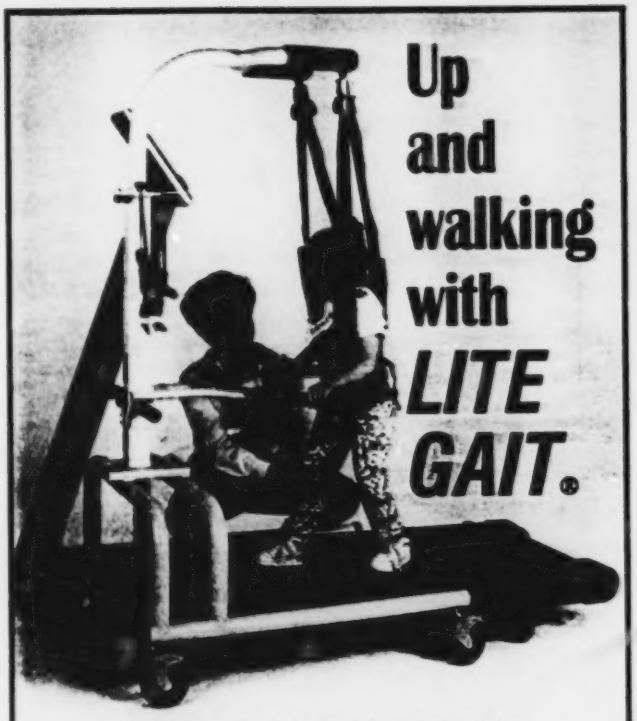
Disability as a set of positive assets

I have a significant disability. I don't minimize it. I've had to find unconventional methods to do my work and live my life. But that's the easy part. Human beings are imaginative and resourceful and can find ways to get things done. The harder part has been confronting institutionalized prejudice and discrimination—like the public policies that kept me from getting a job because I would lose my health insurance.

Parents of children with disabilities can help their kids realize that there are lots of positive elements in the disability experience. I don't mean this to sound like some kind of saccharine inspiration. I just mean I've had a different kind of life experience—partly due to the prejudice and discrimination I've confronted, and partly because being disabled is a different way of existing in the world. It has made me a different kind of historian, a different kind of teacher, a different kind of friend, a different kind of lover, a different kind of citizen than I would be otherwise. My disability isn't just a set of obstacles to be overcome; it's also a set of personal assets I bring into any situation. That's true of every person with a disability. That's what people with disabilities need to be enabled to see about themselves.

I've spoken to many groups of young people with disabilities. I always tell them, "When you have time, sit down alone and make a list of all of the things about yourself that you value—all your personal qualities, talents, insights, whatever. After making that list, think about the way each item may be related to your disability experience. And I'll guarantee you that virtually everything on that list will be somehow related to your disability experience." Rather than encouraging their kids to be heroic, inspiring overcomers, parents should tell children with disabilities to value themselves as who they are—not *despite* their disabilities but *because* of them.

It can be hard for parents to realize their children with disabilities belong to a minority group—a minority group to which the parents don't belong. As empathetic as you are, as much as you care about your child, there is a significant element of your child's experience you will never understand. Because of this, you need to make sure your child has contact with other people with disabilities and has adult role models to emulate. Of course, in many ways, your child will emulate you, but there are things your kid can't learn from you because your child's experience is different. Your child needs to become a part of the disability community. **EP**



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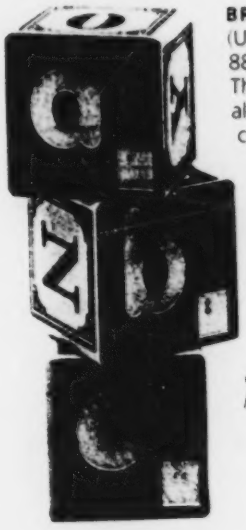
Circle #38

Great Holiday Gifts

By Joanne Oppenheim
and Stephanie Oppenheim

Ask any child what he or she wants for the holidays and the answer is sure to be toys! For kids, toys and the holidays go hand-in-hand. But finding the best matches for a child's interests can be challenging—especially for families with special play needs. As you start making your list—and checking it twice—here is only a sample of the hundreds of new products added to our annual The Best Toys, Books, Videos and Software For Kids. This 1997 edition is available now.

These are kid-tested toys. Many are especially easy to activate, provide interesting sensory feedback, and have long-term play value. As in our book, we describe each product, how to find it, and how to adapt it for optimal learning and play opportunities. To make shopping simpler, we list telephone numbers to help you find the nearest source.



BRAILLE BLOCKS
(UNCLE GOOSE TOYS, $28; 888/774-2046)
These cubes look like classic alphabet blocks with one colorful difference: One face of each has an impressed letter and corresponding Braille cell in the lower right-hand corner. Just right for kids with visual disabilities.
ACTIVITY IDEA: *Play a "find the letter I say" game. Put out three blocks. Ask your child pick the one with the letter or sound you name.*

AMERICAN GIRL OF TODAY
(PLEASANT COMPANY, $82; 800/845-0005)
When you order this beautiful 18" doll, choose from 20 different eye, hair and skin-tone combinations. This year, fit the doll you select with a wheelchair ($32), too. Such a great idea that we gave it our '96 Platinum Award, for toys with the best play value. This year you can also order the specialty party clothes for the holiday *you* celebrate. Available only by catalog.

TRAVELING ANIMAL VET CENTER
(LITTLE TYKES, $20; 800/321-0183)
One step removed from actually visiting the physician, this vet's kit lets kids play doctor on their favorite plush puppy, bear or kitten. Includes a play stethoscope, thermometer, syringe, comb and clip-on bandage. A good way to work through typical fears. Soft animals are not included.

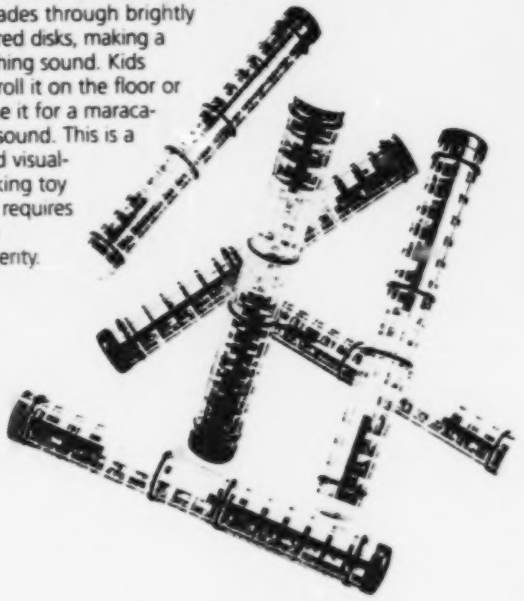
TOYS

911 BEST COPY AVAILABLE

SELECT-A-STATION STEREO

(PLAYSKOOL, $14.99; 800/752-9755)
Fair warning: This is a very loud musical toy. We wish they had included a volume control! That said, it's really amazing! Turn the dial to choose pop, classical, country or easy listening tunes. No tapes or CDs to cope with, and kids get a pleasing sense of "can-do" instead of the usual "don't touch!" The stereo has a carry handle, but if you are traveling we suggest storing it in the trunk. Requires 2 AA batteries.

RAINBOMAKER
(SMALL WORLD TOYS, $17; 310-645-9680)
Turn over this long see-through plastic "rainstick" and a shower of colorful beads cascades through brightly colored disks, making a soothing sound. Kids can roll it on the floor or shake it for a maraca-like sound. This is a good visual-tracking toy that requires little dexterity.



JUNGLE JEFF
(EDUCO, $25; 800/661-4142)
Newest in this company's visual tracking toys, Jungle Jeff has colorful beads to turn, push, count and follow. It comes equipped with suction cups and new attention-grabbing clear tubes covering colorful wires. Ideal for motivating kids to refine dexterity, as well as developing language and concepts (such as position words like "up" and "over"). Jungle Jeff comes with a host of activity ideas, but give your kids time to explore it on their own, too.

SHAPE SORTER WITH MIRROR
(TAG TOYS, $48; #ESC-9; 800/488-4824)
A beautifully crafted shape sorter, this toy comes with five removable plates. The number of holes increases with each plate, allowing kids to work with individual shapes and progress to multiple ones. The box has a mirror to extend children's attention span, motivating them to play longer with this colorful toy.
ADAPTATION IDEA: *For kids with visual disabilities, add textures to each shape and matching opening (for example, affix sandpaper on the triangle block and triangular opening).*

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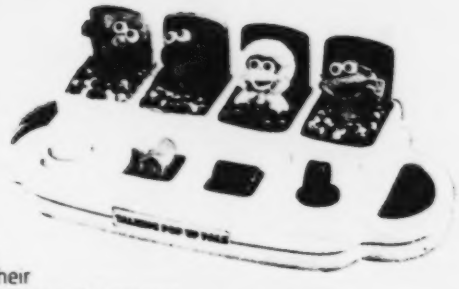
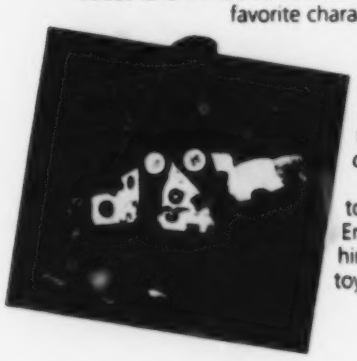
LITTLE PEOPLE SCHOOL BUS
(FISHER PRICE, $14.99; 800/432-KIDS)
Welcome to the '90s! The Little People have undergone some changes recently. They're not only chunkier, making them safe for small children; they are traveling with an accessible rear ramp for wheelchairs. Passengers can also be loaded through a side door or dropped in through the open roof. Wheels make a rachety sound as four Little People and a bus driver roll along.



SESAME STREET TALKING POP-UP PALS AND TUMBLING ERNIE
(TYCO PRESCHOOL. POP-UP PALS, $20; TUMBLING ERNIE, $13; 800/488-8697)
A new twist on a classic toy. Sesame Street fans will be tickled when their favorite characters not only pop-up, but talk! This toy can be adapted for different needs.



ADAPTATION IDEA: *Braille dots can be glued to numbered doors for tactile clues. Stick on character pictures to reinforce visual memory for kids with developmental delays.*

Testers also fell head-over-heels with the easy-to-activate repetitive action of the new "Tumbling Ernie" doll. Each time you sit him down and give him a push, he does a forward roll. A real hands-on toy; the child makes it happen.

BUTTON BORDERS
(ALEX, $13; 800/666-ALEX)
Two plastic picture frames, foil alphabet stickers, colorful buttons, sports and dinosaur charms, and glue: all make this a fun pasting project for boys and girls. Lifting the buttons requires fine motor skill, but since there is no wrong way to decorate the frame, kids get a product they can be proud of.

These are just a few of the many new reviews, including adaptation and activity ideas for products found in the 1997 edition of The Best Toys, Books, Videos and Software for Kids (Prima, $13). To order, call the Exceptional Parent Library at (800/535-1910). For quarterly updates, subscribe to The Oppenheim Toy Portfolio by writing them at 40 East 9th Street, Suite 14M, New York, NY 10003, or visit their website at **http://www.toyportfolio.com.** Subscription price is $12/year.

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TOYS

TOYS
The Tools of Play

by Kathleen H. Murphey

Playtime is one of the essential pleasures of childhood. When children play, they are doing something they enjoy. This is just as true for children who have special needs as it is for others. The world of play can offer a respite from the rigors of daily life and a chance to be active and successful in something they have chosen to do. Play consumes much of a child's time and attention. As with any child, play for a child with a disability is constantly changing. Children change so quickly that play looks different from year to year, even month to month.

According to an old saying, play is the true work of a child. Toys, then, are the tools of this vital activity.

As children grow and become more sophisticated, so does their play, encompassing greater and greater skills and activities. Toys are often sold and stocked by age groups to correspond to this growth. These age groups range from infant to toddler to preschool and beyond, often with subsections for each group.

For a child with one—or multiple—disabilities, the skill level may be more important than the age level when considering a toy purchase. The key is to consider what the child *can* do, either now or as the result of using the toy, and what he or she *likes* doing.

Early Toys

Every aspect of a baby's physical and social world is new. Their play includes lots of sensory experiences, interest in exploring the caregiver and ongoing discovery of what their bodies can do.

Making sense of all the colors, shapes, sounds and sensations in his or her world takes time and experience. It helps if the baby has the opportunity to experiment with different actions and motions, and to explore the sensory features of different things. A crib bar that places bright toys or rattles in the baby's visual field allows opportunities to scan and compare. It can be exciting, too, when the baby inadvertently bats it with a hand, then later discovers he or she can do it on purpose!

As babies get bigger, they enjoy toys with different sensory features: rattles with different sounds; blocks or balls with different textures; toys that spin or pop or chime when pressed, pulled or squeezed. Toys that give an "effect" to the baby's action are especially important because they help develop a sense of "effectiveness"—the feeling of being capable of having an effect on the world.

At any age, the best guide for toy-buying is to focus on what the child enjoys and is capable of doing. A baby with a visual impairment, for example, can enjoy a chime ball that sounds when it is pushed, a squeaky rattle, or a toy telephone with bells and other sound effects. Children whose ability to control their movement is limited may be able to activate a toy that needs only a pat or a pull to start up if you make sure that it is within reach.

Parents can begin very early on to look for preferences your child may have in playthings. As they get older, children with multiple disabilities whose enjoyment of the world centers on the senses may develop a clear preference for certain types of sensations, actions and motions, and play materials. They might take pleasure in a familiar music toy or tape, or perhaps prefer the novelty of a bubble tube or light toy offering a changing visual display. Some may respond best to squeeze toys or balls of different textures. Those are the characteristics to focus on when selecting new purchases.

Moving out and around

As babies become toddlers, play takes on a markedly *physical* character. Playtime becomes the chance to safely test and practice new abilities, whether that is walking, talking, building or imitating.

At this age, children's sense of separateness from the caregiver, as well as their ability to do things on their own are emerging. Movement and active play are central to helping children exercise new abilities while exploring an ever-expanding world independently. Play often means riding, rocking, pushing, pulling, tossing, sliding or rolling some toy or another, trying out different ways of making things go and different places for them to go to.

Child-life therapist Simone Videtto and Jennifer Yirenki discover together the magic of the jack-in-the-box.

When children at this stage are sitting in one place, they are usually still actively trying things out. He or she may conduct experiments with shape sorters, blocks, nesting and stacking toys, bead mazes or simple puzzles. This playful manipulation of objects may start out as an exploration of a toy's sensory features, but soon the child is studying its properties, observing the similarities and differences among the pieces or parts, figuring out

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continued from page 31

how to make them fit together or come apart. Gradually, this experience will help the child begin to recognize color, shape, size and number.

As cognitive abilities (which include thinking, learning and memory) become more sophisticated, children progress to more complex activities. Playing house, for example, may involve the use of developing language skills, the ability to remember, imitate and elaborate on common adult behaviors, and the capacity to react to and interact with another child and his or her version of the "story." Early childhood is also a time when many children are first introduced to art materials. Scribbling with a big crayon can be the start, followed by finger paint, paste, preschool safety scissors, tempera paint with a stubby brush or chalk on the sidewalk.

At this stage, he *process*, not the *product*, is important. Children with delays in motor development may come to this stage a bit later than their age-mates. Because they may be physically larger, parents and professionals need to carefully evaluate such things asriding toys, pushcarts and slides for size and safety.

School days

Having fun with other children is an important goal of play and a skill that develops over time. By the preschool years, many children are able to enjoy playing *around* other children. Eventually, they will play *with* their friends or classmates.

By the time children reach school age, their peers play a bigger role in their lives and the social aspects of play become more important. Although simple games played with a parent or sibling set the stage for learning turn-taking and rules, it is with non-family peers that children learn to get along with others. When children play early playground games like "red light-green light" or non-reading board games such as Candyland, they have to wait their turn, follow the rules, negotiate when to end a game and learn to deal with losing and winning.

Social skills become increasingly important as children move into the worlds of school and neighborhood and have contact with an increasing number of non-family children and adults. As children's skills mature, games of all types allow for the practice and exercise of these abilities in a social setting where children can learn from one another. A young child playing a game of Simon Says or an older child playing soccer with classmates gets a chance to stretch his muscles and work on his balance and coordination. He is also learning to communicate with peers, anticipate events and work toward a goal.

School-aged children typically explore a lot of different interests and forms of creativity. Arts and crafts can foster this process, while offering children a wonderful opportunity to try out different materials to express themselves in a unique way. Some will use crayons, paints, pencils, glue, modeling clay or musical instruments, just for the joy of the activity. Others may practice their techniques and be more intent on the result of their efforts. As children try out different play and recreation activities, it is important to make sure they have the opportunity to make a picture, a sculpture, a song. Whether the result is an abstract whirl of colors, a lopsided candy dish, or a precise

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animal drawing, it lets children have something to be proud of. Craft activities—weaving, model building, jewelry making, needle crafts, woodwork—require specific skills and leave less room for creativity, but they may be of interest to older children. Some become lifelong leisure interests.

For children with disabilities, the issue may be more one of scale than approach. A game of Parcheesi does not require much running, but it, too, can be a chance for a child with a different level of physical ability to have some of the same social opportunities and cognitive challenges that interactions with peers provide. Smaller, easier craft kits that can be completed in a short time and do not require much dexterity may be just the thing for the child who is unable to sustain much energy or attention. The sense of accomplishment that comes from completing a project and the recognition

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When you go toy shopping...

While you are shopping for toys, here are some things to consider:

Is this toy safe for my child? Look for sturdy toys that your child can manage easily. Check the packaging for any safety precautions or warning labels. Make sure that stuffed animals and dolls have their eyes, buttons or other decorations securely attached. If your child puts objects in his or her mouth even occasionally, stay away from toys with small parts that could be swallowed or inhaled.

What skills are emerging for my child? Play is where children try out their new skills. Is your child just starting to reach? To walk? To recognize colors? To communicate with other children? If you are not sure what your child might do next, talk with other parents, teachers or therapists. They may have experience with children whose development is similar to your child's.

How much time is required to play with this toy? Some toys—balls, bubbles, dolls—can be picked up and put down at any time. Some construction toys, games and crafts work better for a child with the energy and attention for longer play sessions.

What are the social demands of this toy or game? Some toys can only be played with solo, others are better played with another child, still others with several playmates. In some instances, children must cooperate to make the game fun, in others they must compete. Consider whether your child is ready to deal with the interpersonal issues that might arise in the course of play.

Is it age-appropriate? "Appropriate" may be in the eyes of the user, as well as in his or her skill-levels. Though a child's abilities and disabilities may influence the type of toy that is appropriate, self-esteem is often a matter of feeling the social tie with one's chronological age group. Both conditions can often be met. A child whose play relies mainly on the senses, for example, may be a music lover. Make sure the tape player you use for an older child is appropriate to chronological age, not a younger child's toy. Along the same vein, children with severe cognitive and communications limitations can still hit a tether ball, play bongo drums, or undertake other motor activities of other children the same age.

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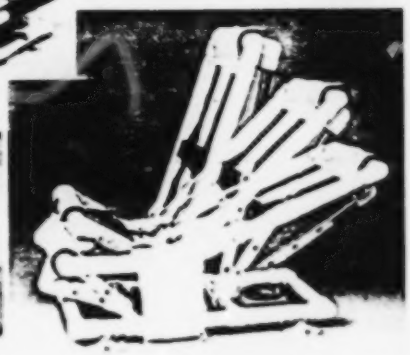

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continued from page 33

that it earns from others—child or adult—can encourage a child's growing sense of competence and worth.

Just imagine!

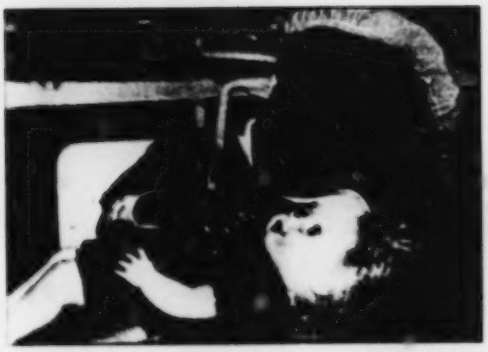
"Pretend play" is a way children explore their social world. This usually starts with their families. For many children the earliest pretend play starts with a baby doll and consists of very simple imitation of a caregiver's most familiar behaviors—feeding, changing, bathing and comforting. Toddlers may mimic the actions and behaviors of the adults they see around them. At this age, toys for household play get a lot of mileage: dolls and doll cribs, kitchenware, toy telephones, brooms, lawnmowers, etc. These help children as they try to figure out the actions of the people around them, first through imitation; later through more elaborate symbolic play.

As children arrive at the preschool years, pretend play becomes more imaginative, dramatic and social. Even the simplest of toys, props and costumes can be used in acting out stories that allow a small child to have a large and important role. Being the doctor, the teacher, the firefighter gives children the opportunity to try to imagine being a grown-up in the world.

When children "act out" difficult things that they have experienced—getting a shot at the doctor's, getting lost at the store—they have a chance to put a different "ending' on the story and to be the actor in control of circumstances instead of controlled by them. In this type of make-believe, children begin to develop and practice their emerging social skills—sharing, negotiating, resolving conflicts.

Fantasy play can also enhance a child's sense of control and power. It is amazing how becoming the magic wizard, the royal empress or the biggest tiger in the jungle can boost self-esteem while providing practice in cognitive skills and problem-solving strategies.

The sense of control and competence available through pretend play can be very helpful for children whose development is complicated by a disability. This type of play can take many different forms. For the child who cannot take good advantage of dress-up and role-play toys, there are smaller "stages" where play action can take place: doll houses and other table-top environments—farms, zoos, schools, garages, etc.



Kwanesha Clarke takes good care of her "patient" at Children's Seashore House.

Children with disabilities may manipulate small-people figures through a story sequence—usually with many changes of plot and character—or they may use action figures such as dinosaurs, superheroes or wild animals in play. This helps express hostile or aggressive feeling. It can also allow the child to fantasize about being the "king of the jungle." Children with severe physical limitations can use different avenues for dramatic play, directing a playmate in moving figures through a scene or narrating a made-up story to a helper who can follow the "creative director's" instructions for illustration.

Another way children provide their own play scenes is by building or constructing them. Manipulative toys come in lots of different sizes, shapes and colors, fitting together in different ways to make a building, a vehicle or a creature. The plain wooden, cardboard or cloth "blocks that the toddler used to stack and knock over are now the stuff from which great highways, villages and launching pads are made. Be sure to have some transportation toys on hand! Other types of building toys require various levels of dexterity: bristle blocks can be made to fit together fairly easily by a small child, but some snap-type blocks require a rather high level of precision. Children who like them, though, may end up using them for years, blending their construction play and pretend play into dramas that may foster imagination and help self-esteem, while providing practice in visual-motor and pre-reading skills.

Have fun!

Toys, play and recreation are part of the joy of childhood, but there is no easy formula for prescribing toys or play activities. Each child has a unique set of abilities, limitations, interests and opportunities. What is fun for one, may be boring for another. Play is something that is freely chosen, so wherever possible, let children select their own activities and play materials. Adults can help by making sure that toy choices are a good fit for the child's developmental level, as well as for motor, sensory and cognitive abilities. Most important: While many play activities promote skill development and learning, children deserve to be able to play because it gives them pleasure and satisfaction. *That* is what makes it play! **EP**

Kathleen Murphey, M.S. is the director of the child life program at Children's Seashore House in Philadelphia, Pa. Seashore House is a pediatric rehabilitation and specialty-care hospital serving children with physical and developmental disabilities. The child life program there is focused on helping children make a positive adjustment to the hospital experience and to illness, disability and treatment. Child life professionals use developmental and therapeutic play, along with other interventions, to help promote optimal functioning, and to help children and families with disabilities have opportunities for fun and success.

Some of the material in this article was adapted from a chapter on Play and Recreation *in* The Handbook of Developmental Disabilities: Resources for Interdisciplinary Care, *Kurt, Dowrick, Lovy and Batshaw (editors), 1996, Gaithersburg, MD: Aspen Publishers, Inc.*

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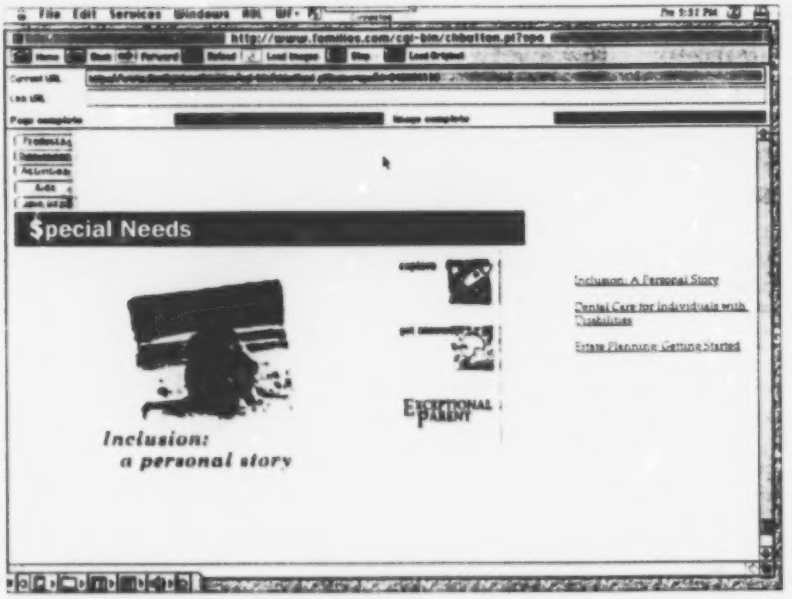

It's official: Family Education Network is on the web! In the months before the launch date—and the weeks since—we have had such great success sharing EXCEPTIONAL PARENT information, advice and contacts. A number of enthusiastic and complimentary letters have reached us, asking for information on the site. We thought this month we would share some of those letters with our readers:

I just got the new issue of EXCEPTIONAL PARENT. Let me congratulate you on starting up a new web site.

As a representative of the Sturge-Weber Foundation, and their web site administrator, I'm glad to see such valuable information making it to the masses! Will you have links to related help groups such as ours?

crs0590@inforamp.net

We are gradually developing "links" with national organizations, such as The Sturge Weber Foundation. We are also asking associations to contribute information to the site, making it even more comprehensive.

I am very excited to see your on-line presence! For many "special" parents, the Search and Respond *capability of your hard-copy magazine has provided a tremendous opportunity to connect with other parents and exchange information on hundreds of "mysterious" conditions that affect our children. Now that you are on the web, this capability will be magnified. The implications are quite thrilling.*

NLeGendre@aol.com

Search and Respond is just the beginning. Our new site will have many opportunities to put readers in touch with each other, as well as the chance to pose questions to experts in the field.

I myself have begun to answer questions e-mailed to our channel through "Ask Our Experts," an important service of the Family Education Network. Here is an example:

I send this e-mail in hopes we can find a proper way to teach our son organizational skills. He was diagnosed at age six with a central auditory processing problem. That means that when the teacher is teaching and other kids make noise, it is difficult for our son to sort things our and stay focused on the teacher. He is now almost twelve and going into seventh grade. We must work with him nightly after school by teaching him material from his books before the teacher starts teaching it so he has a better understanding of the new material. This gives him a jump start.

Is there anything we can do to try to teach him better skills? We live in the Windsor, Ontario area.

agodin@mail.wincom.net

Problems with central auditory processing can make day-to-day school life frustrating. Does your son receive any assistance from a learning disabilities specialist and/or a speech and language pathologist? It could be very helpful.

To get valuable information and to identify specific resources in your area, I suggest you contact: Learning Disabilities Association of Canada, 323 Chapel Street, Suite 200, Ottawa, ON CAN K1N 7Z2; telephone (613) 238-5721. You can also contact the organization via e-mail at ldactaac@fox.nstn.ca.

In addition, thanks to the Learning Disabilities Association of America, in collaboration with EXCPETIONAL PARENT, there is a great deal of information about learning disabilities, including central auditory processing, on the "Special Needs" channel of the Family Education Network.

Future plans for the web (which include adding animation and sound) are already underway, so keep checking the Family Education Network at http://familyeducation.com, and let us know what you think! **EP**

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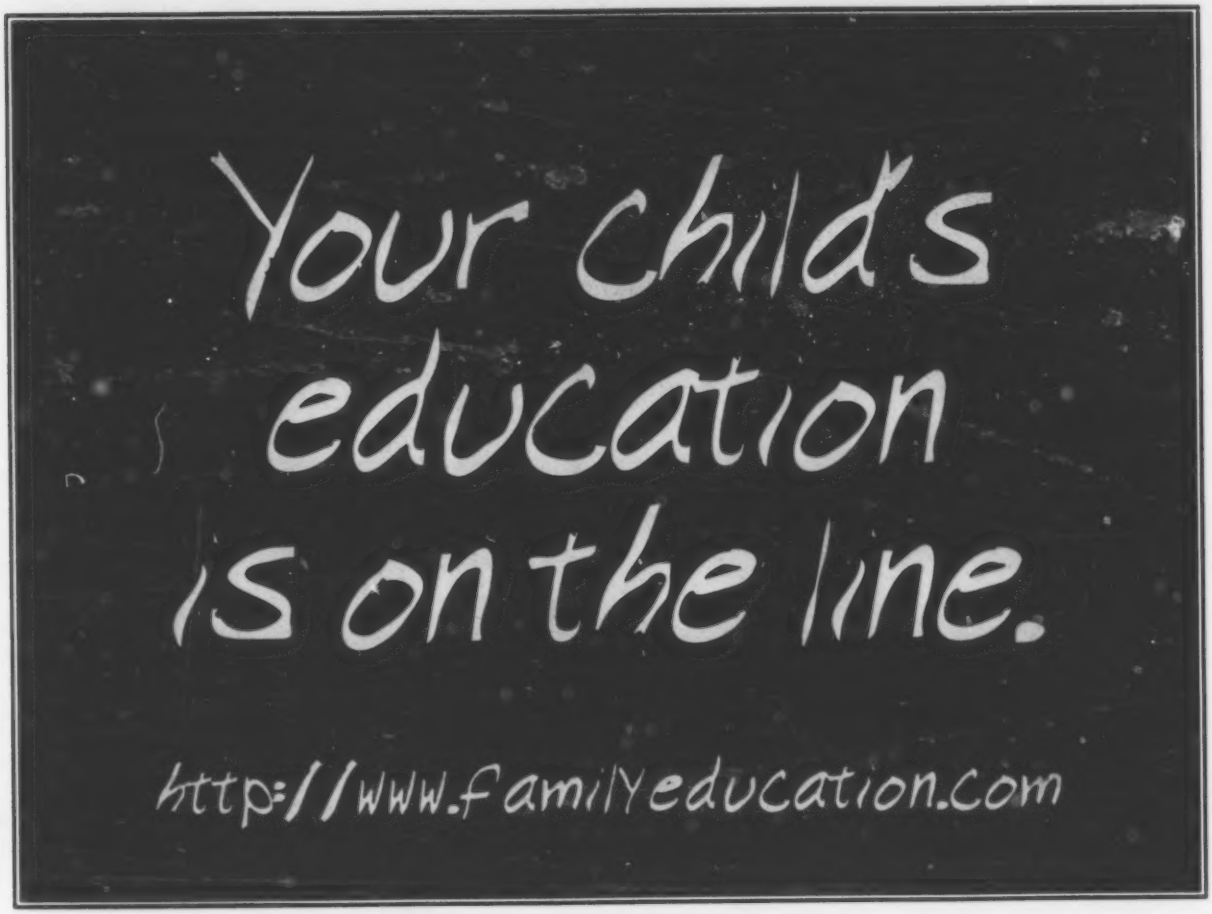

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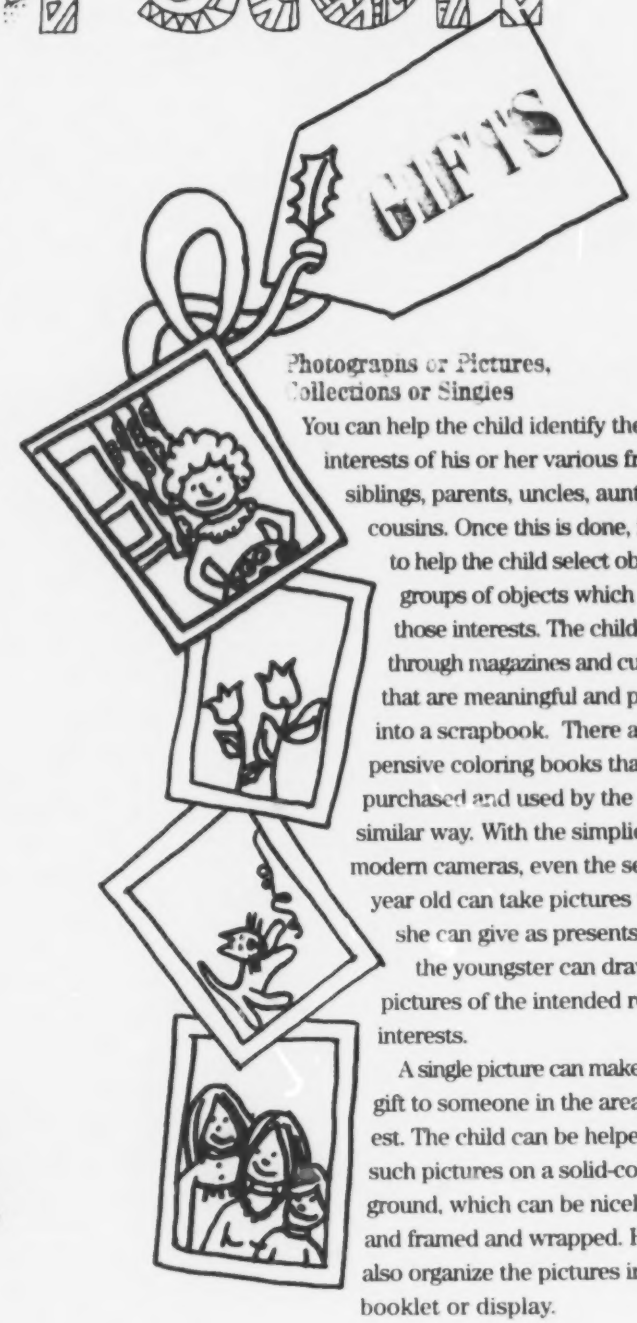
Circle #68

Reprinted from EXCEPTIONAL PARENT, November/December 1973

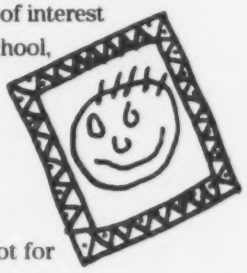
TOYS

fun stuff



During the holiday season we often rediscover the joys of giving as well as receiving. We find ourselves involved with the pleasure of selecting our gifts for our loved ones. When it comes to the child with a disability, we often agonize about the kinds of toys or games that he or she might enjoy and often neglect how much he or she would profit from giving to others.

Children usually do not have much money available for purchasing gifts for their friends and family and find themselves making things. Here, we can be so preoccupied with a child's disability that we may overlook how much pleasure he or she can get out of demonstrating that he or she can produce things of interest and value. In school, young children are often encouraged to make holiday gifts for their parents - but not for anyone else.



Photographs or Pictures, Collections or Singles

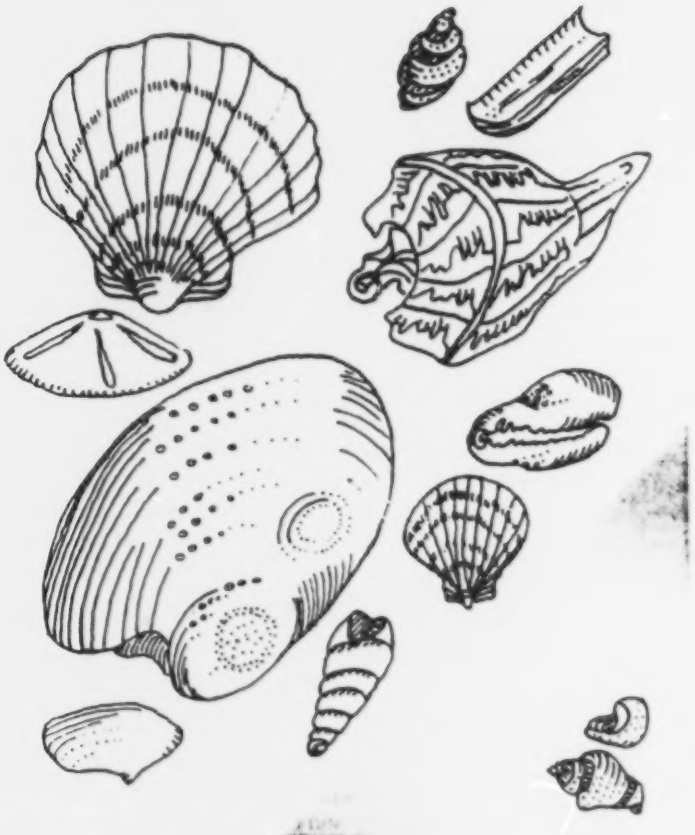
You can help the child identify the favorite interests of his or her various friends, siblings, parents, uncles, aunts and cousins. Once this is done, it is possible to help the child select objects or groups of objects which represent those interests. The child can go through magazines and cut out pictures that are meaningful and paste them into a scrapbook. There are also inexpensive coloring books that can be purchased and used by the child in a similar way. With the simplicity of some modern cameras, even the seven or eight year old can take pictures which he or she can give as presents. And finally, the youngster can draw or paint pictures of the intended recipient's interests.

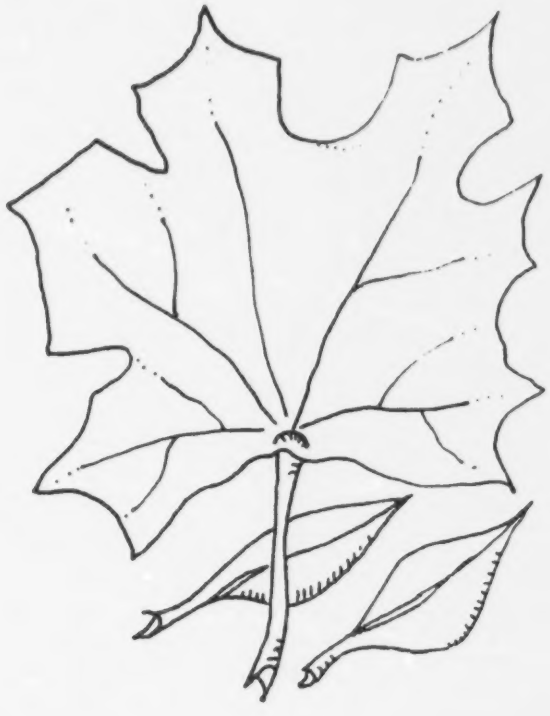
A single picture can make a meaningful gift to someone in the area of his interest. The child can be helped to organize such pictures on a solid-color background, which can be nicely mounted and framed and wrapped. He or she can also organize the pictures in a small booklet or display.

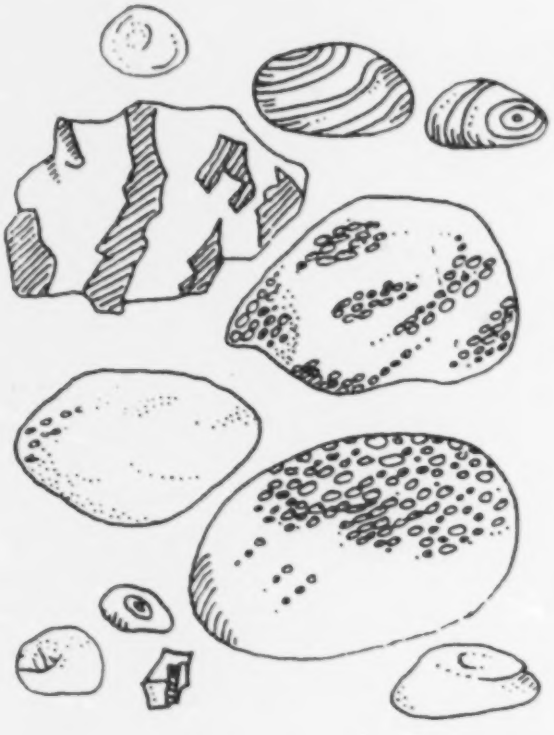
Collection of Favorite Things

The child can also organize nature collections in the areas of his or her own interest or in those of others. During the course of the year, the child can be helped to collect special and pretty stones. In your travels to the seashore or to the country, or even in the neighborhood, there are flat stones that are pretty and many pebbles with interesting colors and shapes. In many parts of the country, there are rocks with shiny mica contained within them. Collecting seashells of different shapes and sizes is a favorite activity of children at the seashore. Finally, there are leaves or flowers that can be collected during many times of the year and then pressed.

The child can begin this process at any time of the year. He or she can be helped to organize and save things that represent reminders of the trips he or she has taken during the year. Again, when these things are mounted or framed or presented in an attractive form, they represent meaningful gifts to people who are really involved and know the child.







READERS TALK ABOUT:
Making Connections Through EXCEPTIONAL PARENT

MAKING SPECIAL FRIENDS

Barbara Staltare and daughter, Gabrielle, pose for the camera.

A few months ago, I wrote a letter to EXCEPTIONAL PARENT about my daughter's frequent arching and extension due to her cerebral palsy and other disabilities. It was printed in the "Ask the Doctor" column in February 1996. A few weeks later I received a lovely letter from Louise Lipton, another parent of a child with similar disabilities.

When I called Louise, I found that her daughter, Emily, and my daughter, Gabrielle, were so much alike that we talked about them for over an hour! Both Emily and Gabi have cerebral palsy and cortical visual impairment. They were on the same medication and we seemed to think they had similar cognitive abilities and similar movement patterns. From that first day we felt a special bond with each other and began a telephone relationship. I suggested that Louise, like me, subscribe to an on-line parents support group called Our-Kids. Once she did, we have been able to keep in touch via the group's e-mail. We now call each other quite often and talk about any new developments concerning Gabi and Emily.

Even though we are very different, we have so much in common that our relationship keeps going. Louise and I have helped each other in ways that no one else could. We share our sad news and our joy, we educate each other about new equipment and treatments and we are there for each other—even if it means we only see each other in the photos that we send in the mail. When Gabi was weaned off her seizure medication recently, it was a difficult time for me and Louise was there for me via computer and phone. I hope that I was able to help her when Emily recently had open heart surgery. In fact, my entire family was thinking of the Liptons that week.

We are now looking forward to meeting in person at EXCEPTIONAL PARENT's Forum '96 in California. We decided that we would only go if we went together. So thanks to EXCEPTIONAL PARENT, I am finally going to meet my special friend.

—Barbara Staltare
Brooklyn, New York

And Louise Lipton writes...

Emily was born two-and-a-half months premature with congenital heart disease. During open heart surgery at three weeks old, she suffered a cardiac arrest which left her with brain damage. As a result, Emily has spastic quad cerebral palsy, cortical visual impairment and is developmentally delayed. During Emily's first year, I longed to find another mother who was dealing with problems similar to those Emily and I faced each day.

Five months ago, Emily's physical therapist gave me last February's edition of EXCEPTIONAL PARENT. I noticed a letter in "Ask the Doctor" from a mother whose daughter was Emily's age and had similar disabilities. I immediately contacted EXCEPTIONAL PARENT and asked them to put me in touch with this mother. After I sent a long letter, I immediately received a call from Barbara. We talked for over an hour about our daughters, Gabrielle and Emily. Since then, we have kept in close contact by e-mail and long telephone calls.

Louise Lipton and daughter, Emily, share a laugh.

Barbara has become a wonderful friend, offering me invaluable advice ranging from medications to positioning equipment, as well as moral support. She has made a considerable difference in my life.

—Louise Lipton
Fort Lauderdale, Florida

READERS TALK ABOUT:

We invite you to contribute to the discussion in future issues of EXCEPTIONAL PARENT:

• **Mobility and The Community:** How has power mobility wheelchairs and scooters helped enhance social and and community participation? We're interested in what your kids have to say too. And–as always–photos!

Write to: Readers Talk, EXCEPTIONAL PARENT, 209 Harvard St., Ste. 303, Brookline, MA 02146, (617) 730-8742 (fax).

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MAKING A KEY CONNECTION

The diagnosis of my daughter, Ashley, with a rare genetic abnormality triggered myriad of emotions. Geneticists were not able to predict what the future held for Ashley, since there were only a handful of documented cases of trisomy of chromosome one.

I kept feeling that there must be other children facing the same challenges as our beautiful daughter. It took me 10 months to gather the courage to write my *Search* letter. I had little hope of a response. At the same time I was terrified that our family might receive some information that we would not be ready to hear.

Ashley and Zachary share a hug.

Five other families connected to ours through that *Search* letter. Wonderful letters brought us new friends: Nine-year-old Erin, who loves to swims, frequently "trashes" her bedroom. I had never thought that the image of my Ashley "trashing" her room could bring such joy. After watching my daughter struggle for months just to hold her head up, the prospect now seemed something to aspire to.

Five-year-old Vinny can take his own lunch money to the cafeteria and is such an avid bike rider that his sixth birthday present was a two-wheeler. Two-wheelers had never entered my mind for Ashley! I had agonized over a simple little riding toy for her just that Christmas.

One-year-old Zachary's photograph bore an uncanny resemblance to Ashley. Only four months younger than her, his developmental progress was very similar, as well.

Erica's parents wrote to say that she had started walking at the age of three and that she shared Ashley's aversion to certain textures.

For the first time since Ashley's birth, I felt that we were not alone in the challenges that we faced.

Those *Respond* letters proved to be valuable in other ways, as well. Since documented cases of trisomy one are so rare, it has been extremely helpful to receive information from other parents that can be passed on to Ashley's doctors and therapists.

Information obtained from other parents on the slow progression of verbal skills played a guiding role in my acquisition of equipment through our state's assistive technology program.

As valuable as the letters and phone calls with other parents were, I still longed for an opportunity to meet with one of these families in person. The opportunity arose unexpectedly when Zachary family moved to Tennessee just as family's return to North Carolina narrowed the distance between us to a short two-and-a-half-hour drive. We set off on a Sunday to introduce Zachary to Ashley—to my knowledge, the first time that two children with trisomy one and their families have been able to "connect" in person.

The visit was a great success for us all. As I watched my daughter's reaction to Zachary, I got the feeling that she was behaving as though he were somehow familiar and safe: a comrade in her ongoing relationships with the people in this world that until that moment had all been different from her.

My hope is that some day Ashley will be as inspirational to another family with a child with trisomy one as the these EXCEPTIONAL PARENT families have been to me.

Shirley Phillips
Henderson, North Carolina.

FINDING A HOME

Joel Dykstra at home with his dad in Marseilles, Illinois.

Reading EXCEPTIONAL PARENT each month often makes our big world seem much smaller. At the beginning of the year we were looking to move closer to my husband's work. We had been looking at homes. Having a child with special needs, however, meant considering more than just buying a house and moving in. It meant finding out what the district had to offer in the line of special services and classes which my son Joel, who has Down syndrome, would require. After much prayer about making the right decision, and visiting the schools and special programs in the area, my Mom called one afternoon to say that there was a positive article on inclusion and the town of Marseilles, Illinois (which we had been considering) in EXCEPTIONAL PARENT. Now, we had our answer: We were moving to Marseilles. Although I had not yet met Julie Hettle, the author of the article, it was reassuring to know that there would be another person in town with whom I had something in common.

I have since met Julie and she is a wonderful person. Our children have become friends. She has given me a wealth of information on area doctors, dentists and the like. She has also been there to talk to me and share with me when things have not gone so well. It really helps just having someone in your situation to talk things over with.

Thank you for helping all of us make connections. Your magazine truly provides a service we cannot receive anywhere else—a common bond with others in our same situation across the country and across the world.

—Kathy Dykstra
Marseilles, Illinois

A PARENTS' GUIDE TO ENTERAL NUTRITION PART THREE: Nutritional Needs

by Mayra Garcia and Lee Barks

When a child is tube fed, parents are often concerned about whether the child's nutritional needs are being met. Just as adults can be the same size and age but have different metabolic rates and need different amounts of nutrients, children do not all have the same nutritional needs for growth. Parents can discuss such concerns with the pediatric dietitian on the clinical team.

Pediatric dietitians are trained to assess a child's nutritional status, evaluate dietary intake, offer nutritional counseling to families and work with the child's physician toward achieving optimal growth and potential.

Children with special needs may have different nutritional requirements as well as different growth rates compared to those of other children. The pediatric dietitian calculates their caloric requirements depending on several factors including age, specific developmental disability, level of physical activity and degree of motor limitations.

ABOUT THIS SERIES:
This is the third in a series of articles on enteral nutrition. Past topics have included an introduction to tube feeding and discussion of caring for the stoma and tube.

Formulas

Formula selection for tube feedings depends on a variety of considerations, including age, nutrient intolerances, caloric content, specific conditions (i.e. kidney disease, metabolic disorders, etc.) and cost.

For most children, birth to ten years of age and without any special nutritional demands, enteral solutions such as Pediasure, Resource, or Kindercal are designed specifically to meet their nutritional requirements. These formulas are complete and balanced. They provide one calorie per milliliter (or 30 calories per fluid ounce, 240 per cup) and are lactose free. About 1000-1300 milliliters (approximately one quart) meet approximately 100% of vitamin and mineral needs. Formulated to drink by mouth or to be given through a feeding tube, they are iso-osmolar, which means that they are easily tolerated by children's digestive tracts and minimize the possibility of diarrhea. However, children with malabsorptive diseases, some metabolic disorders, or protein intolerances however, may require the use of very specific formula preparations designed for their specific condition.

The addition of fiber to formulas may aid children who have problems with constipation or diarrhea. Fiber supplemented formulas usually contain soy fiber, such as Pediasure with Fiber. This may help in controlling diarrhea by increasing the absorption of water into the gastro-intestinal tract, thereby minimizing watery stools. Care needs to be taken, however, when using adult fiber-based formulas for the older adolescent (sixteen and older). These have more than double the dietary fiber of pediatric formulations and may aggravate diarrhea.

Fiber-supplemented formulas may also aid in alleviating constipation by increasing fecal bulk. However, it is crucial to provide sufficient water along with the fiber supplemented formulas to guard against obstructions, conditions which can become quite serious. Providing enough water is often difficult since the children's response to whether or not they are thirsty is not a reliable indicator of their actual need for more water. Using fruit juices such as apple and prune may also help in providing extra fiber to aid with constipation. However, caution is necessary when giving such juices to an overweight child, since juices may be an extra source of concentrated calories.

Sometimes parents think that because enteral formula is not solid food, the formula alone is not enough. There may be a temptation to feed more juice, which is not nutrient-rich—except for some fiber—vitamin C, water and fructose. There is also a temptation to feed baby food or blenderized solid foods through the tube, along with the formula. However, this should be avoided. Solid food can clog the tube and also foster bacterial growth.

Coping With Rapid Weight Gain

When a child has had difficulty gaining weight, the weight gain following tube insertion can sometimes be large and rapid, taxing respiratory and cardiovascular systems. If calories are then restricted due to excess weight gain, a vitamin and mineral supplement may be needed, particularly calcium and iron.

Special attention needs to be paid to the child on anticonvulsant drugs. These drugs decrease the absorption of calcium, vitamin D, and folic acid. If calories are restricted, then the intake of these nutrients may be doubly limited and require supplementation through a multi-vitamin and mineral preparation. Parents can check with the pediatric dietitian to see if a supple-

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ment is necessary and to customize the diet to the child's individual needs.

Some young adults in their twenties have delayed puberty, due to past inability to take in enough calories orally. When they begin to receive enteral nutrition, they are finally able to gain enough weight to experience puberty and their bodies change accordingly. All of these conditions should be taken into account by the pediatric dietitian, so that weight gain is adequate and at the same time slow enough to be healthy.

Making A Difference For Your Child

About six months after tube placement, an appointment with the dietitian for re-evaluation of nutritional status can be a good idea. This is a time when parents and the pediatric dietitian can evaluate growth, formula tolerance, and the activity level of the child. If such an appointment is not automatically scheduled, check with the doctor to arrange one. **EP**

Mayra Garcia, M.S., R.D., is a pediatric clinical dietitian at Arnold Palmer Hospital for Children and Women in Orlando. She works with a variety of patients from birth to twenty-one years including children with spina bifida, kidney disease, as well as children on ketogenic diets.

Lee Barks, R.N., M.N., A.R.N.P., is the president and owner of Developmental Health, Inc., a firm that provides consulting services to rehabilitative and long-term-care programs. She also works as a pediatric nurse practitioner at Pediatrics Plus, a private practice in Orlando, Florida, and as a consultant to the early intervention program at the Arnold Palmer Hospital for Children and Women in Orlando. Lee lives near Orlando with her husband and teenage son and daughter.

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Circle #48

EDUCATION

When Parents Choose Private Education

PART TWO: Religious Schools and Homeschooling

by Barbara J. Ebenstein

About this series:
This is the second of two articles dealing with the obligations of school districts to students with disabilities whose parents have chosen a private, rather than public, educational setting. The first article in the series (September 1996) covered the issues of tuition reimbursement and publicly funded special education services. This article will deal with the issue of special education services for children attending religious schools or being educated at home.

The First Amendment of the United States Constitution prohibits government entanglement with religion.* This means that the government may neither promote nor inhibit religious activity. The government is barred from giving financial aid to religious schools because to do so would promote the teaching of religious beliefs.

Although school districts are government agencies that cannot support religious education, they may offer some special education services, such as therapies, for children attending private religious schools. Often, these services will be provided at a "neutral" setting, such as a nearby public school, so as to avoid providing services that might promote religious training. However, in a 1995 case, *Benjamin P. v. City of Lackawana*, parents of children with disabilities attending parochial schools argued that the special education services for their children were provided so far from their schools that the children missed a substantial amount of class time while they were being transported back and forth. The Court agreed with the parents and stated that although the school district was not required to provide services at the parochial school, neither was it barred from doing so.

School districts may provide special education services that do not directly promote the teaching of religion. For example, in a 1993 case, *Zobrest v. Catalina Foothills School District*, the U.S. Supreme Court ruled that the school's district's provision of a sign language interpreter for a deaf child at a Roman Catholic High School did not violate the First Amendment because an interpreter merely transmits information without adding to or subtracting from religious training.

Although the Court in the *Zobrest* case did not specify other special education services that could be provided on-site at private sectarian schools, four current cases are asking circuit courts in different parts of the country to answer this question. Although these four cases all involve religious schools, decisions in these cases will also help clarify the services a school district must provide to children with disabilities who attend any type of private school. (For more on the federal court system, see sidebar on page XX.) All four cases involve services that cannot be provided in a "neutral" setting—teaching aide, sign language interpreter and consultant teacher. Because these services facilitate the child's inclusive placement, they must be available in the classroom. The cases are:

• *K.R. v. Anderson Community School Corp.* (Indiana): This case involved a seven-year-old child with multiple disabilities who attended a parochial school and required an aide. Although the school district provided therapies for the child at a nearby public school, the district refused to provide the aide. The parents lost their due process hearing, but prevailed at the district court level. The school district then appealed to the 7th Circuit Court, which agreed with the district that private school students placed by their parents are not entitled to the same range of benefits guaranteed to other children. The parents have petitioned for U.S. Supreme Court review. Meanwhile, parents in the 7th Circuit states should expect their school districts to provide no more services than required by the OSEP (U.S. Office of Special Education Programs) formula, which is the legal minimum. (The OSEP formula, covered in detail in "Part One: Tuition Reimbursement and Special Education Services," September 1996, requires only that the school district spend a comparable percentage of federal IDEA [Individuals with Disabilities Education Act] money on privately and publicly placed children. However, because the federal government provides so little special education funding, use of this formula can result in the provision of very limited services, or no services at all. As long as the school district has a rationale for the way it allocates these IDEA funds, it may

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Circle #53

Federal Courts

Parents who do not agree with their school district regarding a child's evaluation, IEP or entitlement to services—including services provided to children attending private schools—can turn to legally established due process procedures. This means that those parents have the right to an impartial hearing, an appeal to a state review office and a further appeal to the federal courts.

A case first enters the federal court system by receiving a full trial and decision in the federal district court for that part of the state. Following that, either side may appeal to the federal circuit court serving the region that includes their state or U.S. territory (see below). A circuit court decision may be appealed only to the U.S. Supreme Court. However, very few such cases are accepted for review.

A circuit court decision sets a precedent to be followed in the states within that court's jurisdiction. Lower courts in jurisdictions where there has been no circuit court precedent are influenced by opinions from other jurisdictions.

1st Circuit: Maine, Massachusetts, New Hampshire, Rhode Island, Puerto Rico
2nd Circuit: Connecticut, New York, Vermont
3rd Circuit: Delaware, New Jersey, Pennsylvania, Virgin Islands
4th Circuit: Maryland, North Carolina, South Carolina, Virginia, West Virginia
5th Circuit: Louisiana, Mississippi, Texas
6th Circuit: Kentucky, Michigan, Ohio, Tennessee
7th Circuit: Illinois, Indiana, Wisconsin
8th Circuit: Arkansas, Iowa, Minnesota, Missouri, Nebraska, North Dakota, South Dakota
9th Circuit: Alaska, Arizona, California, Hawaii, Idaho, Montana, Nevada, Oregon, Washington, Guam, Northern Mariana Islands
10th Circuit: Colorado, Kansas, New Mexico, Oklahoma, Utah, Wyoming
11th Circuit: Alabama, Florida, Georgia

(continued from page 44)

choose to serve private school students only with a particular disability or to provide only one or two limited services.)

• *Russman v. Board of Education of the Enlarged City School District of the City of Watervliet* (New York): The IEP of Colleen Russman, a teenager with developmental delays, placed her in an inclusion program with an aide and consultant teacher. The parents asked the school district to provide these same services at a parochial school. Both the district court and, very recently, the 2nd Circuit Court found in favor of the parents and required the school district to provide the services at the parochial school. The courts stated that because the provision of these services at the religious school would not cost any more than the provision of the same services at a public school, it did not place an undue burden on the district.

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Circle #31

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Parents in the 2nd Circuit states should expect their school districts to provide special education services to students in private schools as long as it does not cost substantially more to provide these services in that setting.

• *Cefalu v. East Baton Rouge Parish School Board* (Louisiana): The parents of a teenager with a hearing impairment wanted the school district to provide a full-time sign language interpreter at his parochial school. The parents lost their due process hearing, but prevailed in the district court. The school district is appealing this case to the 5th Circuit Court. The Circuit Court's decision in this case will set a precedent for school districts in the 5th-Circuit states.

• *Fowler v. Unified School District No. 259* (Kansas): The parents of a child with a hearing impairment wanted the school district to provide a full-time sign language interpreter at the child's sectarian elementary school. The parents prevailed at the due process hearing, but that decision was reversed by the state review officer. It was then reversed again by the district court, which ordered the district to provide the interpreter, finding that the provision of this service was not an undue burden on the school district. This case is on appeal to the 10th Circuit Court, whose decision will set a precedent for the states in that jurisdiction.

An earlier case, *Goodall v. Stafford County School Board* (Virginia), set a precedent that is still followed in states of the 4th Circuit. In that case, the parents requested a sign language interpreter at a private religious school. They lost all due process hearings and court decisions. The U.S. Supreme Court chose not to review this case. Parents in the 4th Circuit states, therefore, should expect their school districts to follow the OSEP formula.

PARENTS HAVE THE RIGHT TO MAKE EDUCATIONAL CHOICES FOR THEIR CHILDREN.

The different courts hearing these cases have applied no uniform policy or standard interpretation. Because the courts have had no clear precedent to follow, most of these cases flip-flopped between decisions favoring parents and decisions favoring school districts as they worked their way through successive appeals. Each Circuit Court decision took a different approach and relied on different reasoning. Such discrepancy makes the issue ripe for review by the U.S. Supreme Court, and it is likely that the Court will choose to review one of these cases within the next year or two. School district policies will continue to differ in different parts of the country until the U.S. Supreme Court

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reviews a case dealing with this issue, thereby setting a precedent that courts throughout the country must follow. Until then, parents who want to know the likely policy of a particular school district should look into the most recent circuit court rulings in that region.

Homeschooling

All states have compulsory education laws requiring parents to send their children to school. Those parents who chose to send their children to state-licensed private schools may do so without interference from their school district. Those parents who wish to educate their children at home must comply with state laws mandating periodic inspection and review of the homeschooling program.

The situation becomes more complex when parents wish to homeschool children with disabilities. No state laws deal with this question directly; however, states that permit children without disabilities to be educated at home must permit parents to educate children with disabilities at home or face potential legal proceedings under Section 504 of the Rehabilitation Act, which prohibits discrimination based on disability by agencies receiving federal funds.

Children with disabilities who are homeschooled are entitled to the same evaluation, identification and IEP development services as all other children in the school district. Some parents also want the school district to provide in-home related services, such as speech therapy and consultant special education teachers. The ability to obtain such services varies from state to state. Each state has a regulation that either deems homeschools as "private schools" or not. If the state considers homeschools as "private schools," homeschooled children with disabilities are entitled to the same services as children placed in private schools by their parents. However, if the state does not consider homeschools as "private schools," homeschooled children with disabilities are entitled only to an evaluation and IEP. Parents should ask their state's department of education about pertinent state regulations on this issue.

Informed choices

Parents have the right to make educational choices for their children. At the same time, they need to know that choosing certain educational options may have the consequence of restricting a child's entitlement to special education services. Until the U.S. Supreme Court clarifies some of these issues, entitlement to these services is one factor parents must weigh when considering private education for children with disabilities. **EP**

Barbara J. Ebenstein is a partner in the law offices of Ebenstein & Ebenstein in New York City. She lives with her husband, Dr. John E. Handelsman, and their three daughters, Sarah, 15, Leanne, 13, and Risa, 10, who has a disability.

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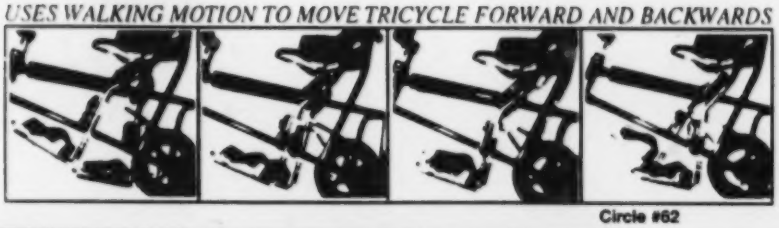

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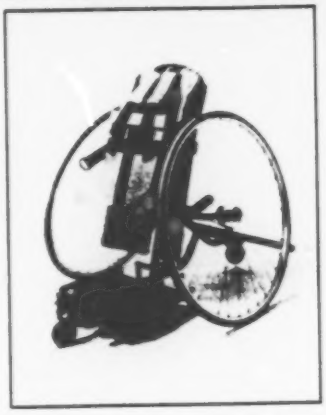

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Help! My Baby Can't Breastfeed

by Sue Murvich

Many pregnant women daydream about holding and feeding their newborn babies. But this dream doesn't always come true when a baby is born prematurely and whisked off to an intensive care nursery equipped with special equipment, doctors and nurses.

In such circumstances, parents typically experience mourning reactions similar to those occurring with a death of a child. Even if the parents are assured that the baby is in good condition, they may feel grief over the loss of their "dream baby." Parents often feel a sense of loss at being unable to perform even routine care like feeding, bathing and diapering their infant.

First steps toward breastfeeding

The mother of a preterm infant can actively contribute to the recovery, growth and development of her child by expressing (pumping) breast milk and bringing it to the hospital. The breast milk is frozen until the premature baby is able to receive oral feedings.

Due to an immature digestive system, weak or absent suck reflex, breathing difficulties and/or other medical problems, a premature infant usually receives fluids and nutrition intravenously or through gavage tube-feedings. Intravenous feedings, also called "total parenteral nutrition," are given through an infant's veins, bypassing the digestive system completely. Gavage tube-feedings are given through a temporary feeding tube that is threaded into one nostril or the mouth, down the throat and esophagus, and into the stomach. Breast milk is usually tube-fed to a premature infant until he or she is able to to suckle adequate amounts at the breast. Normally, an infant begins suckling when he or she has reached a gestational age of 32 to 34 weeks. However, the transition to total breastfeeding is not usually complete until a gestational age of 40 weeks (the infant's original due date).

Mothers who express breast milk can give a preterm infant special benefits the child can get from no other source:

- Human milk is easy to digest. The preterm infant with an immature digestive system can derive maximum caloric benefits from breast milk feedings.
- The protein, breast milk of mothers who deliver preterm babies is higher in the first four to six weeks of lactation. This makes it the optimum feeding choice for preterm infants, who require a higher-protein diet.
- Human milk contains enzymes and hormones that are particularly important to the maturation of the digestive system and nervous system.
- Human milk contains defenses against infection. Antibodies in breast milk give the premature baby's immune system protection from serious bacterial infections, and respiratory viruses.

Janet Paquette breastfeeds her 5 week old daughter. Juliette was born April 12, 1996, at 26 weeks gestation.

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Lactation consultants, health professionals with special training and experience in breastfeeding, work with ICN staff to provide support to mothers who are pumping and/or breastfeeding. These professionals teach the correct use of electric breast pumps and procedures for handling, storing and transporting expressed breast milk. They also provide tips on maintaining breastmilk production, caring for themselves and stimulating infants to suck. Finally, lactation consultants can provide support during the transition to breastfeeding and assess infants' suckling progress.

Electric breast pumps can be rented from hospitals, durable medical equipment suppliers, private-practice lactation consultants or some WIC agencies (Women, Infants and Children—WIC—is a government program that provides vouchers for the purchase of certain foods). Breast pumps can also be rented directly from manufacturers. (from $1 to $2.50 a day). Some ICNs have funds available (often through the Children's Miracle Network) to cover rental fees when insurance coverage is denied. The use of a breast pump is usually required until an infant reaches what would have been his or her due date, and longer if there are other medical problems.

As soon as the baby is medically stable, parents are encouraged to engage in a technique known as "kangaroo care" or "kangaroo holding," which involves holding the diapered baby upright, skin-to-skin, on dad's chest or between mom's breasts. This simulates the infant's warm, pre-birth environment as he or she feels the parent's rhythmic breathing and hears his or her heartbeat and voice. When this technique is used regularly, premature babies show a number of benefits, including improved heart rate and breathing pattern, decreased crying, longer quiet sleep periods (important in conserving calories for growth), more rapid weight gain and faster transition to breastfeeding. Kangaroo also stimulates the mother's breastmilk production.

During visits to the ICN, parents are also encouraged to

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train their baby to suckle by encouraging the infant to suck on a finger. The suck-training technique involves stroking the infant's cheeks, lips and palate (roof of the mouth) to stimulate a sucking response. The parent can also use a finger to exert gentle pressure downward and forward on the tongue; this helps the infant develop the tongue coordination that will be needed later for breastfeeding.

Alternative feeding methods

Hospitals have started teaching parents how to gavage tube-feed their preterm infants, allowing infants to be discharged earlier. Their parents tube-feed them at home while they make the transition to breastfeeding, bottle-feeding or an alternative feeding method. The average duration of at-home tube-feeding is two weeks.

As an infant's gag reflex improves, it becomes more difficult to thread a feeding tube down his or her throat, and parents are understandably anxious to discontinue this feeding method. They can do so once an infant can take adequate nourishment orally—by breastfeeding, bottle-feeding or alternative feeding method. However, because the transition to total breastfeeding takes time, infants who have started breastfeeding are likely to need supplemental feedings for several weeks. Bottle-feeding may seem the most logical and convenient type of supplementation; however, for the infant, bottle-feeding and breastfeeding are very different experiences. Differences include nipple texture and length, as well as the mechanisms the infant must use in suckling and swallowing. Switching an infant back and forth is likely to lead to "nipple confusion"—or even a preference for the bottle—prolonging the transition time and leading to frustration for both parent and child.

Fortunately, alternative feeding methods including cup-feeding, spoon-feeding, finger-feeding and supplemental nursing systems allow infants to receive supplemental breastmilk or special formulas by tube while suckling at the breast. If a baby is having difficulty latching onto the breast, cup-feeding or finger-feeding would be the alternative methods of choice. If the baby can latch onto the breast, a supplemental nursing system would be preferred. To prevent aspiration (breathing of fluid into wind pipe or lungs during feedings), parents must be trained in the use of these methods and the infant must have a sufficiently strong gag reflex.

• *Cup-feeding* teaches an infant to bring his tongue down and forward (part of the normal tongue movement needed for breastfeeding). It also

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allows the infant to pace his feedings, allowing time to swallow. During cup-feedings, the infant is swaddled in a blanket and placed in an upright sitting position. The cup is placed against the infant's lower jaw or lip, so the infant can use his tongue to lap up milk like a kitten. For older infants, the lower rim of the cup rests against the upper lip, and the child's tongue remains below the cup. When the cup is angled so liquid touches the baby's lips, he will sip and swallow at his own pace.

• *Spoon-feeding* is similar to cup-feeding, but uses a small medicine spoon or the soft, pliable Medela Cup Feeder, which has a control valve and self-refilling reservoir that maintains a steady supply of liquid at its lip.

• *Finger-feeding* uses the gavage feeding tube or supplemental nursing system (see below) taped to the parent's finger instead of to the breast. Alternatively, a periodontal syringe (plastic syringe with a tapered, curved tip) or soft, plastic eyedropper may be used. Finger-feeding combines nourishment with exercises that train the infant to later accept and compress the nipple properly—keeping his tongue down, forward and cupped. When the baby draws the parent's finger into his mouth, he also takes the tube, syringe or eyedropper. When the baby sucks properly, he will be "rewarded" by drawing liquid into his mouth. An eyedropper is especially useful for an infant who tends to chew rather than suck on the parent's finger, because it allows parents to "reward" sucking attempts by squeezing the eyedropper bulb to release a few drops of liquid. Eventually, the infant will begin sucking the liquid out of the eyedropper on his own.

• *Supplemental nursing systems* allow an infant to simultaneously nurse at the breast while receiving supplemental feeding through one or two soft tubes taped next to the mother's nipple and attached to a bottle or bag hung around her neck. When the baby takes the nipple into his mouth, he also takes the tube. Breastfeeding then proceeds normally. Supplemental nursing systems are made by Medela and Lact-Aid. The tubing and syringe from a gavage tube-feeding set can also be used for this purpose. **EP**

This is one of a series of articles prepared in collaboration with the National Perinatal Association (3500 E. Fletcher Ave. Ste. 209, Tampa, Florida 33613-4712). NPA is a multidisciplinary association of individuals and organizations concerned with perinatal (time of birth) health issues from preconception through infancy. Sue Murvich, MS, RD, works as a registered dietitian and lactation consultant at Gunderson Lutheran Hospital in La Crosse, Wisconsin.

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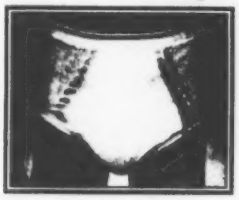

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Presidential Policies

Where do the candidates stand?

BILL CLINTON

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In 1992, the President said America must not rest until we had a national disability policy based on three creeds: inclusion, not exclusion; independence, not dependence; empowerment, not paternalism. He committed to meet America's challenges and protect America's values in ways that matter in the daily lives of all Americans, by creating opportunity, demanding responsibility, and building community.

Together we have made great progress toward achieving these goals. Our economic strategy to reduce the deficit, expand trade, and invest in our people is paying off. The deficit is down 60 percent. We have 10.5 million more jobs, and the lowest combined rate of unemployment, inflation and mortgage rates in 28 years. Interest rates are historically low, and home ownership has reached a 15-year high.

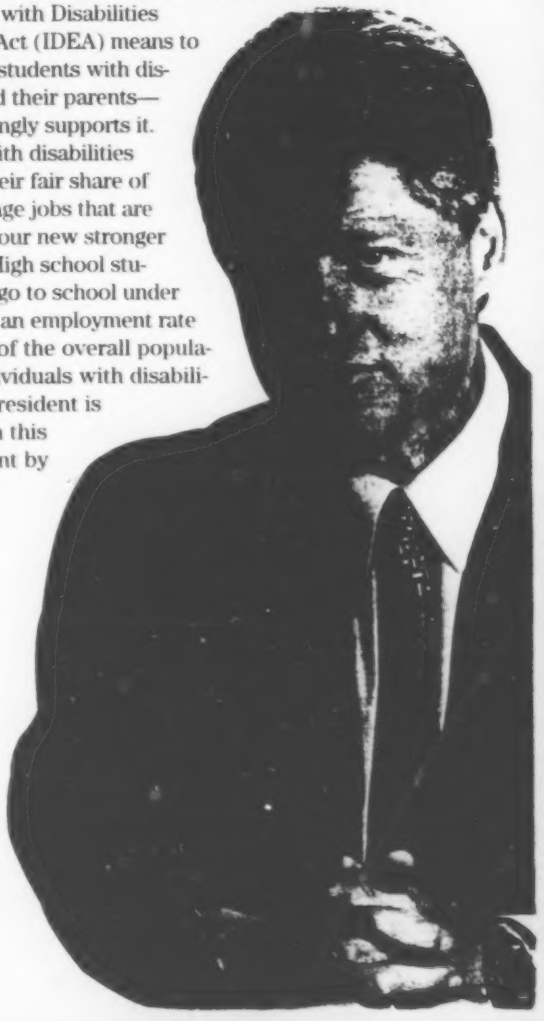
Fifteen million Americans can now keep more of that they earn because President Clinton expanded the Earned Income Tax Credit. His leadership in boosting the minimum wage just gave 10 million working Americans a raise, including the millions of Americans with disabilities who face extra costs for accessible housing and personal assistance. Because the President fought for the Kennedy-Kassebaum Bill, 25 million Americans will have new health security—insurance companies will no longer be able to deny coverage to anybody with a preexisting condition, or to anyone who changes jobs or has a family member who gets sick. Our communities are more secure, too. Violent crime is down all across America. The Crime Bill will put 100,000 new police on our streets, and the Brady Bill is keeping handguns from 60,000 fugitives and felons.

As we move into the next century, the President believes there is no more important challenge in America than to cherish our children and strengthen our families. The very first piece of legislation he signed as President was the Family and Medical Leave Act, giving parents time off for crucial family matters. This legislation, which had been vetoed twice, has already been used 12 million times—and it hasn't hurt the economy one bit. The President is now working to expand Family Leave for parent-teacher conferences and doctors' appointments, so parents can be both good parents and good workers, without fear of losing their jobs.

President Clinton rejected Republican proposals to end the Medicaid guarantee of meaningful health benefits, preserving crucial coverage for six million persons with disabilities, including one million children. Without Medicaid, families might be pushed into poverty to pay for a child's medical care, or forced to give up their jobs or pay for an institution. The President also vetoed a budget bill that would have significantly cut cash assistance to most families with disabled children on social security—families who are struggling to care for a child at home, faced with extra costs for home modification and equipment, and lost income because a parent cannot work full-time.

This Administration's greater flexibility in granting state waivers has spurred an increase in home- and community-based programs—the number of people with developmental disabilities served in home and community waiver programs nearly doubled to 122,000 in 1994.

President Clinton knows how much the Individuals with Disabilities Education Act (IDEA) means to millions of students with disabilities and their parents—and he strongly supports it. Students with disabilities must get their fair share of the high-wage jobs that are opening in our new stronger economy. High school students who go to school under IDEA have an employment rate twice that of the overall population of individuals with disabilities. The President is building on this achievement by



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supporting efforts like high school technology programs that guide promising students to colleges and careers in science and technology. He is making sure that people with disabilities are included in school-to-work efforts. The President is also fighting to increase IDEA's focus on outcomes for children and cutting unnecessary paperwork.

Over the last four years, the President has appointed a highly-qualified group of people with disabilities to high-level, policy-making positions. Many of these appointments are to key positions not directly related to disability.

President Clinton is committed to offering individuals with disabilities the opportunity to build independence through rehabilitation services and work incentive programs. By enacting the National Voter Registration Act ("Motor-Voter" Bill) and Telecommunications Reform Act, President Clinton is making voting easier and communications technology more accessible.

The President's strong commitment to the Americans with Disabilities Act has opened up town halls, schools, transportation systems, workplaces, groceries, restaurants and theaters to millions of Americans. President Clinton vigorously enforces the ADA and other critical civil rights laws that prohibit discrimination against people with disabilities—he is protecting these laws from attempts to weaken them.

Building a stronger America—for all Americans—means citizens with disabilities must be able to exercise their full rights and responsibilities, live as independently as possible, and be productive throughout their lives. That's why President Clinton is working to strengthen civil rights protection—his 1997 budget proposal calls for a 3.9 percent increase in funding for ADA enforcement and compliance.

President Clinton will continue fighting for Americans with disabilities. Without imposing premium increases, the President's proposed balanced budget protects health care benefits for 37 million Medicare beneficiaries, including 4.9 million Americans under 65 with disabilities.

The President will continue to vigorously enforce the ADA, with a balanced approach that emphasizes voluntary compliance whenever possible. He remains committed to expanding employment options and working to maintain an effective IDEA and improving student outcomes. President Clinton knows that America does not have a person to waste; people with disabilities are among our most precious human resources.

PEOPLE WITH DISABILITIES ARE AMONG OUR MOST PRECIOUS HUMAN RESOURCES.

continued on page 56

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Presidential Policies continued from page 55

ROBERT DOLE

The rights of people with disabilities has been a personal crusade for me for 27 years. On April 14, 1969, I rose to give my first speech as the junior Senator from Kansas—the anniversary of the day I joined the disability community during World War II. I chose to speak about something I knew a lot about personally, something I cared about deeply—helping people with disabilities achieve opportunity and independence.

In that maiden speech, I spoke about exclusion that was too often a part of the lives of people with disabilities—including children:

"People with disabilities have always known exclusion—maybe not exclusion from the front of the bus, but perhaps from even climbing aboard it; maybe not exclusion from pursuing advanced education, but perhaps from experiencing any formal education; maybe not exclusion from day-to-day life itself, but perhaps from and adequate opportunity to develop and contribute to his or her fullest capacity."

We've come a long way since then—we still have much farther to go. But if we ever doubt the progress we have made, let us look to our successes in the education of students with disabilities. Twenty years ago, millions of young people were not allowed into school simply because they had a disability.

The Individuals with Disabilities Education Act—IDEA—has changed that. In 1975, I helped craft the first IDEA legislation. And on the morning of the day I resigned from the Senate, I went to the Senate floor to encourage my colleagues to pass the latest reauthorization of IDEA. I believe Senator Frist—together with his colleagues—have crafted a good bill, and one that deserves all our support.

But much work remains. For example, I am very concerned that school reforms—such as GOALS 2000—have ignored students with disabilities. For example, GOALS 2000 aims for a 90-percent high school graduation rate. Even without reform, the graduation rate among non-disabled students is 83 percent. But among students with disabilities, the drop out rate has grown—from 40 to 48 percent. For this reason, I got funding for a National Academy of Sciences study of how well school reforms are serving students with disabilities.

As President, I will press for full funding of IDEA. As I have said in the past, there are many programs funded by the Department of Education that really belong back in the States. But, in my view, funding special education—providing financial support for the education of students with disabilities—is a proper Federal responsibility. Even in a time of tight budgets, with the savings we can realize from downsizing other programs in the Department of Education, we can significantly boost IDEA funding.

As President, I will also push for greater school choice for students with disabilities. I have also been a longtime supporter of school choice. Let's give parents vouchers so that can pay for the school they think is best for their child. Although school choice is good for children without disabilities, it is even better for children with disabilities.

Let me tell you what else Bob Dole will do for people with disabilities. As President, I pledge to people with disabilities and their families that I will:

•Press for full participation of Americans with disabilities in all walks of life, and vigorously and fairly enforce disability rights laws—such as the Americans with Disabilities Act.

•Implement a three-fold plan to improve health care for children with disabilities:

1) Develop new ways to increase health care insurance choices for people with disabilities. Republicans showed this year that real health care insurance reforms were possible—by passing the Kassebaum-Kennedy health care reform bill. But we have more to do;

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2) Improve the training of health care professionals in the special ealth care needs of children and adults with disabilities; and

3) Explore ways to use new technologies such as the Internet to improve the kinds of health care information available to people with disabilities.

•Promote home and community based services, including creating a new program for children. Bob Dole will end the institutional bias in the Medicaid program. I will not allow children or adults with disabilities to be forced into institutions. We will give people the options they want and need—not what Washington bureaucrats want to give them.

• Provide greater economic opportunity for people with disabilities. As President, I will bring to this nation's attention the startling poverty among people with disabilities, and work to bring people with disabilities to the same standard of living as other Americans. I will jump start a new national initiative effort to increase employment by convening a White House conference on employment of people with disabilities. I bring together the nation's top CEOs, small business leaders, and advocates for people with disabilities and ask them to provide a concrete plan—including supported employment.

• Combat crimes and abuse against children and adults with disabilities. One of the big promises of ADA—an accessible environment—means little if people with disabilities are afraid to leave their homes. And the best community residence is unacceptable if parents feel their child may be abused, and personal assistance is worthless if people are afraid of their attendants. Yet, although people with disabilities have said in surveys that crime is one of their biggest fears, no one in Washington seems to be hearing them. But Bob Dole has. Two years ago, I sponsored an amendment to a crime bill to cover people with disabilities under hate crime laws. And in a Dole Administration, fighting crime and abuse against people with disabilities will be a top priority.

• Put the rights of people with disabilities on the international human rights agenda. Three years ago, I encouraged the State Department to start reporting on human rights abuses against people with disabilities worldwide—and they have. Over 500 million people worldwide have disabilities, but still too often they are locked away and denied opportunity. We must use our moral authority to end this discrimination and abuse. **EP**

EDITOR'S NOTE: EXCEPTIONAL PARENT notes that all three Presidential candidates were asked to participate in this article.

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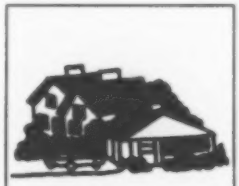

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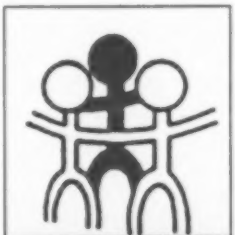

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WHAT'S HAPPENING

With accessible movies for all
In one of the largest settlements to date under the American Disabilities Act, United Artists Theater Circuit Inc., one of the largest motion picture exhibitors in the country, recently agreed to make their theaters more accessible to people with mobility disabilities. Under the class-action settlement, UATC has agreed to modify more than 2,000 theaters nationwide over the next six years, making auditoriums accessible for people who use wheelchairs.

With approval of the settlement, eligible patrons (those with mobility disabilities who attended one of California's 24 UATC theaters built or modified since 1982) are entitled to a portion of the settlement fund. Those interested in obtaining a claim form should call 1-800-306-2779. All claims must be postmarked by November 12, 1996.

Neurofibromaotis: A Guide for Educators
The Neurofibromatosis Foundation Inc. is offering a new booklet entitled *Neurofibromatosis: A Guide for Educators*, geared for education professionals. Written by Harvard Medical School neurologist Bruce Korf, M.D., an authority on NF children, the 12-page booklet offers pertinent information and recommendations on the cognitive, behavioral and physical manifestations of the disorder.

For a copy of the booklet, send $1.00 (postage and handling) to NNF, 95 Pine Street, 16th Floor, New York, NY 10005, or call 1-800-323-7938.

Making Inclusion Successful
A recent study sponsored by the National Down Syndrome Society in New York, NY, found inclusion a rewarding experience for both students and teachers alike. The survey of parents and teachers across the nationwas conducted to determine the outcome of inclusive practices.

The majority of the teachers who participated in the study said their classes benefited from working with a student with Down syndrome. Almost all teachers who responded said the experience was enjoyable, while some called it the most rewarding of their careers.

However, survey results indicated there is room for improvement: More appropriate teacher preparation and more time for conferences between teachers, therapists, parents and support personnel is needed to create a more inclusive-friendly environment; flexibility and willingness to modify classroom materials is key for successful inclusion. Other tips include allowing students to participate in developing the rules or the design of the lessons; discouraging students from constantly seeking help and rewarding them for independence; and encouraging friendships with classmates.

For a copy of the survey, send $10 to the NDSS Educational Challenges Program, 666 Broadway, 8th floor, New York, NY 10012-2317.

The New Virtual Classrooms
Laurel Springs Independent Studies Program has released a pre-K-12 academic curriculum recognized by colleges and universities across the country, and is the first home school in America to offer complete on-line curriculum as well as the opportunity for students to earn their high-school diploma using personal computers.

Located in Ojai, CA, Laurel Springs uses the Internet to educate its students in a worldwide virtual classroom. The school also employs special education professionals who tailor the program to the needs of each participant. Teachers assign projects and correspond with students through e-mail. Students conduct research missions, making virtual field trips around the world.

For more information about the curriculum and class offerings, call (805) 646-2473, or write them at P.O. Box 1440, Ojai, CA 93024. You can check out their Internet home page at http://www.laurelsprings.com. **EP**

FUNNY AS A CRUTCH by Frank Bernard, Jr.

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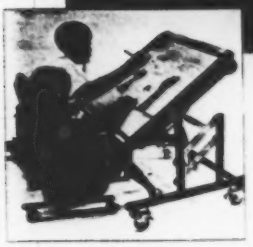
NEW PRODUCTS



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Children who need a place to work, play and create will find it at the Convert-Able Table. The table offers three snap-on tops to accommodate a variety of activities: a melamine desktop, an art easel and a sensory stimulation bowl. A push of a button adjusts the height from 21 to 37 inches high, making the table accessible to wheelchairs, standers, gait trainers, chairs and a variety of other positioning aids. Plus, the top is angle-adjustable from zero to 90 degrees. Four dual locking casters keep the Convert-Able Table in place when in use, while still providing mobility. Art and accessory bins are available for storing art supplies, writing tools, books and papers.

R.E.A.L. Designs (Rehab and Educational Aids for Living), Dolgeville, NY 13329

Circle #294

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ADAPT-TA-BIKE converts any standard 16-, 20- or 24-inch bicycle equipped with coaster brakes to a therapeutic bicycle for use by children with disabilities. Each kit includes a set of wheel supports with 10-inch semi-pneumatic wheels, an adjustable back support and foot supports with pulley system. The system can be transferred from one bike to another, allowing ADAPT-TA-BIKE to grow with the user.

Creative Adaptations, Milton, NH 03851

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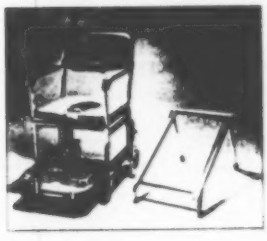
TUB SLIDE SHOWER CHAIR

The Tub Slide Shower Chair is a combination commode and shower chair designed to enable teens and young adults with disabilities to transfer to and from the tub without leaving the chair. This chair features an extension frame that clears the edge of the tub, allowing the user to slide the seat over into the tub for showering. The chair also offers sufficient clearance to fit over a toilet.



R.D. Equipment, West Barnstable, MA 02668-1233

Circle #296

COLUMBIA STROLLER BASE

The Columbia Stroller Base converts the Columbia Car Seat to a positioning stroller for children with physical disabilities who weigh between 20 and 102 pounds, offering an alternative to traditional wheelchairs. The lightweight aluminum frame folds for storage and transport. The stroller features large wheels and an easy-to-use locking mechanism to secure the car seat to the frame.

Columbia Medical Manufacturing Corp., Pacific Palisades, CA 90272

Circle #297

PROP-IT

PROP-IT is a portable book holder designed to enable hands-free reading of all types of books. The holder features an elastic page holder that keeps the book open while allowing easy page turning. PROP-IT supports a variety of reading materials from small paperbacks to 10-inch wide, three-inch thick books. When not in use, PROP-IT folds flat for storage and transport.

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Circle #298

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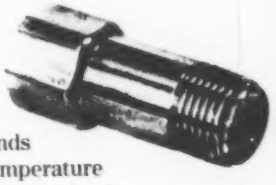

Memry Corporation, Brookfield, CT 06804

Circle #299

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT*'s "Free Product & Information Card." Readers can circle a number on this issue's card to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.*

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Fragile X Syndrome: Medications for Aggressive Behavior?

by David Hirsch, M.D.

Q Our 14-year-old son has fragile X syndrome. Although he had routine chromosome testing a number of years ago, the results of that test were normal. The fragile X diagnosis was confirmed only recently by direct DNA analysis. *[EDITOR'S NOTE: For more information on fragile X syndrome and its diagnosis, see "Fragile X Syndrome," ASK THE DOCTOR, June 1995.]* Our son doesn't seem to have many of the prominent physical features of fragile X, but he has mild to moderate mental retardation, and it seems he is falling farther behind each year. My other major concern is some behavioral symptoms he is exhibiting—primarily aggressive, sometimes violent, behavior towards me, his classmates and, occasionally, his teachers. We have tried behavior modification at home and at school with limited success.

Are there any medications that can safely be used to help control his aggressive behavior? I certainly do not want him to be sedated, but I am afraid that if his behavior does not improve, he will fall even farther behind.

A Increasingly, professionals are realizing that behavioral symptoms are often an important component of certain medical problems, such as fragile X syndrome and, in fact, can often lead to severe problems if not adequately recognized and treated. I strongly believe that if not dealt with appropriately, the behavioral problems seen in fragile X and other developmental disorders can often lead to poor school performance which, in turn, may cause a child to fall farther behind his or her peers academically.

Behavioral symptoms, if any, vary greatly between individuals with fragile X syndrome and also may vary in the same individual with age. However, aggressive behavior, sometimes with violent outbursts, is not uncommon in adolescents or even younger children with fragile X syndrome. Nevertheless, before considering the use of medications, doctors should perform a comprehensive medical evaluation to rule out physical problems that might be contributing to such behavior. For example, doctors should investigate the possibility that the child is having seizures—specifically complex-partial seizures—a type of seizure that includes altered consciousness and often "automatisms" (robot-like behaviors such as running, fumbling with objects or clothing, or lip-smacking). Sometimes complex-partial seizures may appear as aggressive or violent behavior. Other medical problems that cause physical pain—such as chronic infections or gastrointestinal problems including constipation, cramps or gastroesophageal reflux (severe heartburn), may also lead to aggressive behavior, especially in an individual who lacks sufficient language ability to express his or her discomfort.

Environmental overstimulation or situational stress caused by changes in schedule, surroundings or school staff may also contribute to aggressive or other behavioral changes. In addition, it is important to remember that all teenagers—including those with mental retardation—have to deal with the physical and emotional changes of adolescence. Difficulty in coping with these changes can be another source of stress.

If medical and social/environmental issues have been ruled out as a cause for your son's behavior, one more evaluation should be done prior to the use of medications specifically intended to deal with aggression. If possible, a psychologist or psychiatrist experienced in evaluating individuals with developmental disabilities should evaluate your son for psychological problems such as depression or obsessive-compulsive behaviors. If a psychological problem is the source of your son's aggressive behavior, it is important that he receive appropriate treatment for that condition. And even if no psychological problem is diagnosed, a

In preparing his answer to this month's question, Dr. Hirsch consulted FRAGILE X SYNDROME: DIAGNOSIS, TREATMENT AND RESEARCH, 2nd edition (1996, Johns Hopkins University Press) edited by Randi Jenssen Hagerman, M.D., and Amy Cronister.

Also contributing to this month's column was Michael R. Tranfaglia, M.D., medical director of the FRAXA Research Foundation. Dr. Tranfaglia is the author of A MEDICATION GUIDE FOR FRAGILE X SYNDROME (1995), available from FRAXA (P.O. Box 935, West Newbury, MA 01985; $25 postpaid, all proceeds fund fragile X research). Dr. Tranfaglia lives in West Newbury, Massachusetts, with his wife, Katie Clapp, and children, Andy, 6, and Laura, 4, both of whom have fragile X syndrome.

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psychologist or psychiatrist with experience in developmental disabilities may be able to work with your son's pediatrician in selecting an appropriate medication to deal with his aggression.

Many professionals believe that typical behavior modification techniques are largely unsuccessful in dealing with the specific behavioral problems associated with fragile X syndrome. In some cases, these techniques seem to make problem behaviors worse. Behavior modification appears particularly ineffective in treating aggression. Modification of an individual's environment, including the way people in that environment react to inappropriate behavior, is more likely to be effective than attempts to reshape the individual's behavior. [See, "Why Does Samantha Act That Way?" September 1996.] Unfortunately, however, there is no scientific evidence that any particular behavioral strategy is effective for individuals with fragile X syndrome.

Similarly, there have been no specific studies of the use of medication for the treatment of behavioral problems in individuals with fragile X syndrome. However, studies involving individuals with autism and mental retardation can provide useful guidelines. Based on these studies and their personal experiences, many professionals believe certain medications can be helpful in the treatment of aggressive and violent behavior in individuals with fragile X syndrome.

Carbamazepine (Tegretol) and valproic acid (Depakene), two well-known anticonvulsants, can be useful in controlling aggression in some individuals, especially, some studies suggest, if certain EEG (electroencephalogram) abnormalities are present. (However, several other studies indicate that these medications are equally effective in individuals with normal EEGs.) Both drugs appear to be mood-stabilizers, and one theory is that they work by decreasing the excitability of the limbic system—the region of the brain hypothesized to control emotion.

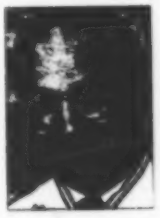
Clonidine (Catapres), a medication typically used to lower blood pressure, has been helpful in calming and improving the attention spans of some children with attention deficit hyperactivity disorder (ADHD)—children who do not necessarily have fragile X syndrome. This medication also seems to help control aggressive behavior in some individuals with fragile X syndrome, especially when they also exhibit some of the symptoms characteristic of ADHD. Guanfacine (Tenex), a similar drug, may be equally effective and less sedating.

More recently, the selective serotonin reuptake inhibitors (SSRIs) have been successfully used to treat episodic aggression in some individuals with developmental disabilities. I have seen these work especially well when there seems to be a component of depression or obsessive-compulsive behavior. One example of this class of medications is fluvoxamine (Luvox). Related medications such as trazondone (Desyrel) and buspirone (BuSpar) may also be effective.

It's also important to be aware of medications that should probably be avoided. These include stimulant medications, such as Ritalin, and tranquilizers, such as Valium, Ativan or Xanax (although I have occasionally used Ativan successfully on a very short-term basis in individuals with fragile X syndrome for acute, or extreme, situations involving aggressive behavior). In general, antipsychotic medications are also counterproductive, having a tendency to increase—rather than decrease— aggressive behavior in individuals with fragile X syndrome. One exception is the atypical antipsychotic, risperidone (Riperdal), which I have found to be useful in certain cases.

Should you and your son's doctor decide to address his aggressive behavior with medication, you will need to work together to monitor his response. It will be important that your son undergo periodic evaluations to monitor for any side effects of treatment and to make any necessary dosage adjustments. Under no circumstances should any medication be started or stopped abruptly without consulting a physician experienced in the use of those medications.

The pharmacological treatment of fragile X syndrome and other complex developmental problems changes almost daily. For up-to-date information, contact the FRAXA Research Foundation (P.O. Box 935, West Newbury, MA 01985; 508/462-1990; 508/463-9985, fax; fraxa@seacoast.com, e-mail; http://www.worx.net/fraxa) or the National Fragile X Foundation (1441 York St., Ste. 303, Denver, CO 80206; 800/688-8765; 303/333-4369, fax). **EP**



In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT*'s Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.*

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).*

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A QUARTER CENTURY OF CARING

Portability Act 1996

by Richard Epstein

We are now beginning to see some significant changes in health-insurance law at the federal level. The most notable of these changes is the new "Portability and Accountability Act of 1996," signed into law in August. Different parts of this new law will take effect at different points throughout 1997. At the same time, what you see today is not necessarily what you will get in the near future. As with any new law, rules may be changed or reinterpreted as they are applied, technical amendments may be issued at some future point, and exceptions may be made to some of the provisions in certain cases. The important thing is to be aware of the *scope* of the law and how it *could* affect your situation so that you can keep on top of the changes, benefits and your overall insurance situation.

One of the main concerns that the new law addresses is the issue of the precarious link between employment and insurance coverage. Many parents have been deeply concerned about the possibility of losing their jobs, or about changing jobs, because of the potential impact on health-insurance coverage. In the past, such changes have meant a possible loss of benefits due to exclusions for pre-existing conditions.

Under the new law, when an individual switches jobs, there will generally be no exclusion of coverage on the basis of pre-existing conditions. However, that provision applies *only* if the individual was enrolled in a health-insurance plan for at least 12 months before the change, and as long as the switch from that health-insurance plan to the new group coverage occurs within 63 days of the change. Though several parts of the Act that relate specifically to health insurance issues will not take effect until July 1, 1997, the 12 months of prior enrollment in a health-insurance plan starts accumulating as of July, 1996.

The law also makes it possible to consider switching from a job that includes group health-insurance coverage to one that does not include coverage at all. It does so by guaranteeing that people in such situations will be able to purchase individual health-insurance policies without being concerned about pre-existing-condition limits. In that case, however, the individual must have been enrolled in a previous health-insurance plan for at least 18 months. In these cases, the 63-day change-over period stipulation still applies, but with a difference: Benefits under COBRA, Medicare, Medicaid, or other health-insurance programs must first be exhausted before switching to an individual health-insurance policy. The 63 day-period starts when those benefits run out.

Benefits of the Act also apply to self-employed individuals. It will significantly increase the income-tax deduction for health-insurance expenses for the growing pool of self-employed people. In addition, the Act provides that some expenses related to long-term care insurance may be deductible. Check with your accountant for details.

The Act provides additional protection to employees covered by self-funded plans as well. These plans are not purchased from an insurance company, but are established by a company, union, association or government agency. In these situations, if changes are made that involve a reduction in benefits, the plan's sponsor must either notify the participants of that change within 60 days, or must institute an ongoing system of providing a complete plan description every 90 days.

Another concern with which the Act deals is renewal of coverage. Health-insurance plans are now generally prohibited from refusing to renew coverage for an individual because of a pre-existing condition or a disability.

Limiting limitations; expanding opportunities

Health-insurance plans are prohibited under the Act from imposing rules or limits that discriminate against an individual on the basis of a disability. However, health-insurance plans may continue to limit specific benefits, as long as those limitations apply to all people insured under the plan, rather than case-by-case in terms of an individual with a disability. For example, an insurer may decide to limit benefits

continued on page 64

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

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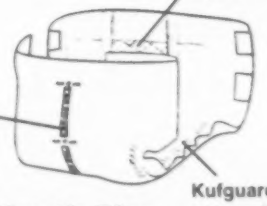

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Circle #49

continued from page 63

for the treatment of mental illnesses as a field of medical coverage. Or it may limit benefits for speech therapy, physical therapy, or durable medical equipment such as wheelchairs.

The Portability Act also paves the way for a entirely new approach to health insurance: "Medical Savings Accounts" (MSA). Next year, a pilot program will be launched in which eligible individuals will be able to purchase a special "high-deductible health insurance plan" and, along with it, establish a Medical Savings Account. Money deposited in the MSA is intended to be used to pay medical costs not covered by these policies. That money will receive special treatment in terms of federal income taxes.

Some parents of children with disabilities will not find MSAs useful; others will find value in the potential tax benefits. Given the complexities of the tax system, it is important to review your situation with an accountant and an attorney before making a decision about participating in the Medical Savings Account program. Since the number of MSA participants will be limited, it may be worthwhile beginning to think about such a review as soon as possible if you're considering participating in the program.

Be aware: The Medical Savings Account concept is designed as a pilot project, not a permanent arrangement. The test period for the program is four years—from January 1, 1997, to December 31, 2000—and is limited in terms of the maximum number of participants. If you are interested, check with your accountant for details.

Legal issues

There are a couple of other important provisions in the Act that respond to concerns about Medicare fraud. A new Medicare fraud preven-

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tion program has been established, for example. For the most part, this program is more likely to affect providers than beneficiaries. However, it could result in a new beneficiary-educational program designed to help increase understanding of Medicare rules.

Another provision is the Incentive Program, designed to encourage Medicare beneficiaries to report possible cases of Medicare fraud. Although the details have not been worked out yet, the basic concept is involving the beneficiary in identifying possible cases of fraud by medical and other health-care providers. If Medicare beneficiaries report instances of possible fraud and those reports result in a recovery of funds, the person who originally made the report may receive a portion of the money recovered. The program is also intended to allow Medicare beneficiaries to recommend changes in program rules that may save money. You are sure to get mail on this when it starts up.

A critical section of the law to be aware of is one that emphasizes possible criminal penalties for knowingly disposing of assets in order to qualify for Medicaid. Since that provision has not yet been applied, it's unclear what the process will be for determining or dealing with possible violations. However, if you are considering applying for Medicaid benefits for a child with a disability, and you have assets that may affect the child's eligibility status, it is important to check with an attorney or with a local protection and advocacy service agency before making any decisions.

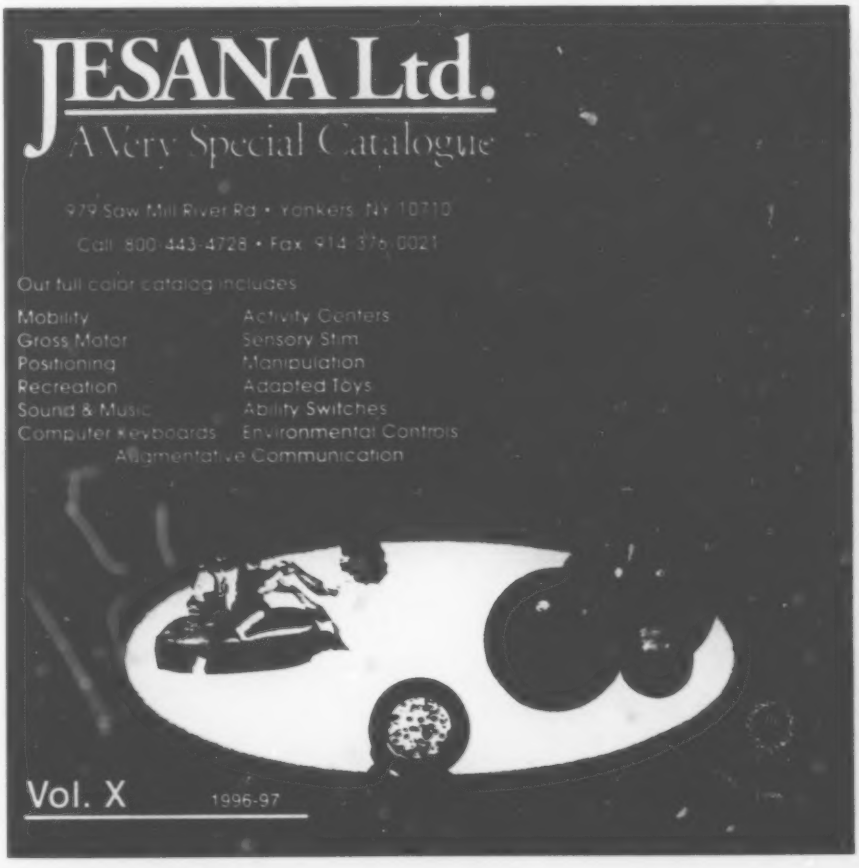
Remaining gaps

Although the "Portability and Accountability Act" offers some important changes for parents of children with disabilities, it is by no means perfect. First, it deals only with issues related to the continuation of health insurance, and thus may not provide help to individuals who are applying for health insurance coverage for the first time.

Second, the final version of this Act omitted an important concept that had been included in an earlier proposal: A guarantee of "parity." That guarantee was intended to ensure equality of benefits in the coverage of treatment for both physical and mental illnesses, in terms of reimbursement amounts and life-time maximums. It's unfortunate that the guarantee of parity was not included in the final version of the Act.

State laws matter

The overview of the "Portability and Accountability Act of 1996" presented in this article is preliminary. The major provisions of the Act have yet to go into effect. Furthermore, the Act allows state law to take precedence in certain situations. This would occur when a state has passed insurance reform laws that offer greater consumer protection than does the federal statute. Rules may differ state to state. It is important to know state laws in this arena. The best place to check for specific information on your state law is the state Department of Insurance. **EP**



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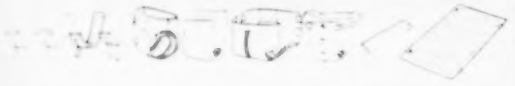

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I certify that the statements made by me above are correct and complete. —Stanley D. Klein, Editor in Chief

OBRA Payback Trusts

by Theresa Varnet

Q My mother recently died, leaving no will. She left an estate worth approximately $300,000. I have one brother and one sister, so the estate will be divided in three equal shares. The problem is that my brother has a history of mental retardation and mental illness; he is unable to support himself. He presently receives SSI, Medicaid, Section 8 (housing assistance) and food stamps. I fear that he will loose eligibility for all of his government benefits when my mother's estate is distributed. Can he disclaim the inheritance?

Is there any way he can receive his inheritance without losing his government benefits?

A No and Yes. No, he cannot disclaim the inheritance. Yes, his eligibility for government benefits can be saved by a new estate-planning option.

There is a new legal way that your brother will be able to keep his eligibility for government benefits and still receive the benefit of his inheritance. Recent changes in Federal Medicaid rules have made it possible for a person with a disability and under the age of 65 to remain eligible for Medicaid even if he or she receives money or assets in excess of $2,000 from a direct inheritance, law suit, divorce settlement or other financial windfall, *if* that windfall is placed in a qualifying trust.

In August of 1993, President Clinton signed the Omnibus Budget Reconciliation Act (referred to as OBRA '93) which changed the Medicaid rules pertaining to the transfer of assets. The new law also contains another noteworthy exception which allows parents who are in need of nursing-home care to transfer their assets to an OBRA Payback Trust for the sole benefit of a child or grandchild with a disability. Under the old law, a person could not qualify or requalify for Medicaid if he or she transferred assets to another person within a certain time frame of applying for Medicaid. This meant that persons with disabilities who rely on Medicaid, and parents of persons with disabilities in need of Medicaid funded nursing-home care, had to "spend down" their assets to $2,000 or wait 30 months to qualify for Medicaid.

The bad news is:
1) Congress has extended the so-called look-back period from 30 months to 36 months for outright gifts and to 60 months for transfers to most trusts. The look-back period is the time period during which a Medicaid applicant or recipient is not allowed to make any gifts to anyone for the transfer of assets);
2) Congress has eliminated a person's ability to disclaim an inheritance. Prior to OBRA '93, if a person with a disability was in line to receive an inheritance, and if the receipt of this inheritance would jeopardize his or her eligibility for government benefits, he or she could simply disclaim the inheritance. OBRA '93, however, treats such disclaimers as the transfer of an asset; a person will lose his or her eligibility for Medicaid if he or she disclaims an inheritance.

The good news is there were two important exceptions carved out in the new legislation that help individuals with disabilities and parents of persons who are disabled. The new rules allow:
1) An individual with disabilities under the age of 65 who receives funds to remain eligible for Medicaid by transferring his or her funds to an irrevocable OBRA '93 Payback Trust. The trust is called a "payback" trust because if there are any funds left in the trust when the beneficiary dies, the state is entitled to be paid back for the full amount of Medicaid moneys paid on behalf of the beneficiary; and
2) Parents or grandparents, who require long term nursing home care, to transfer their own funds to an OBRA Payback Trust for the sole benefit of a child who is disabled. Once accomplished, they can become eligible for Medicaid without a waiting period. This exception answers the prayers of parents who have worried about what would happen to their son or daughter with disabilities if all their money had to be spent on their own nursing home care.

These two OBRA '93 exceptions offer exciting planning opportunities for lawyers working with persons with disabilities and their families in the areas of guardianship, personal injury, divorce, estate planning and elder law planning. However, if Medicaid funds are changed to a Block Grant formula, these estate planning options will probably be lost. This is one more reason to contact your legislator and let him or her know if you are opposed to Medicaid money coming to the states in the form of Block Grants.

It is important that families not confuse the OBRA '93 Payback Trust with the special needs or supplemental needs, trusts recommended by estate planners for parents of persons with special needs. Not *all* persons with disabilities (only persons under 65 who have a disability as defined by the

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Social Security Administration) can qualify for an OBRA '93 Trust. Also, an OBRA '93 Trust requires that the State be paid back from the remaining balance of the trust assets after the death of beneficiary. As such, the OBRA '93 Trust does not take the place of, or reduce, the need for families to leave a will with a special needs trust for their son or daughter. It is, however, a wonderful safety net for those families who failed to plan and have left their child an inheritance which otherwise would have resulted in the loss of Medicaid.

The average attorney is not likely to be familiar with the OBRA '93 trust. Lawyers drafting these trusts require knowledge in trust law, tax law, Medicaid law and guardianship law. My recommendation is that a parent seek advice from an attorney who is a member of the National Academy of Elder Law Attorneys. While not all members of the Academy will be familiar with the OBRA '93 trust, it is more likely that attorneys who belong to this organization will have a working knowledge of this new trust. **EP**

Theresa Varnet is a partner with the law firm of Spain, Spain & Varnet, P.C. of Illinois and Massachusetts. Theresa is a former teacher, master's level social worker and parent of a daughter with tuberous sclerosis and mental retardation. She has been an active advocate on behalf of persons with disabilities and their families for over twenty-five years.

Because regulations vary from state to state, readers are reminded to consult appropriate national association or legal professionals before acting on the advice provided in this column.

Send questions to: Future Planning, Exceptional Parent, 555 Kinderkamack Rd., Oradell, NJ 07649.

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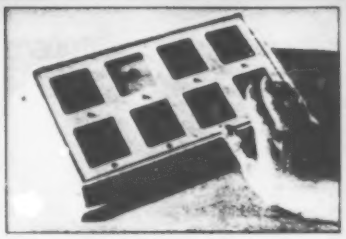

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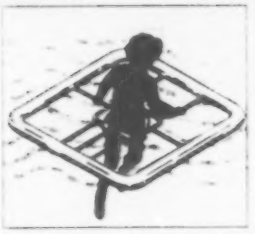

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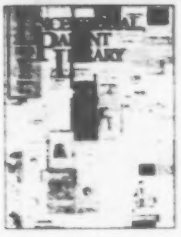

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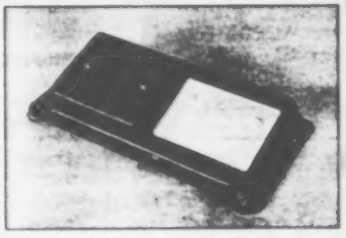

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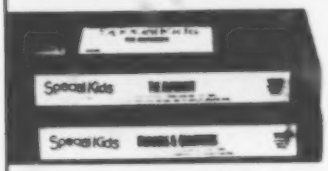

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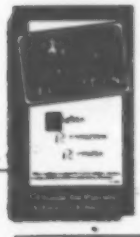

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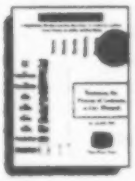

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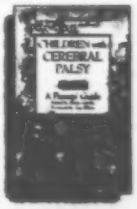

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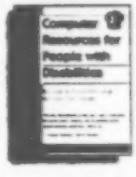

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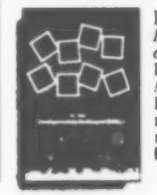

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Beautiful Jenny

by Jessica Rabold

Jessica Rabold (right) spends a day with brother Jarrod and sister Jenny at Arnold's Park near Okoboji, IA.

Mom's Turn:
Jessica wrote this poem about her sister for an English assignment last year. At fourteen, Jessica is the oldest of three and hopes to be a child psychologist. Jennifer is 13 and their brother, Jarrod, is twelve. Jessica's poem is a very special one to our family. I am proud to share it with others.

My younger sister, Jenny, has Down syndrome. One night as I was sitting at my computer trying to think of a poem to write for English class, my sister walked into the room and suddenly I had no trouble writing stanza after stanza. This poem did not take me long to write...my sister's inner and outer beauty form into words so effortlessly.

Jenny

When I see a sunset, or a shadowy sky,
I think of the person who puts a twinkle in my eye.
When I see someone laughing or when I hear a sweet voice sing,
I think of the person who invented these things.

When I see a chocolate sundae, or a clear swimming pool,
I think of the person whom some call a fool.
When I see her crying, it breaks me up inside,
and when I have a secret, she's always there to confide.

The words of other people sting my very heart,
but she just smiles through it and is never torn apart.
She is much braver than I'll ever be,
nothing seems to hurt her, though it really hurts me.

Her happiness has always rubbed off on me,
and when I am feeling down, it is her that I go see.
I hear her happy cries and I see her sad tears;
she knows I'll always be there to calm her fears.

This special person whom I love with all my heart,
is a little girl, whom from I can never be torn apart.
She is my sister.

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: **Children's Page,** *EXCEPTIONAL PARENT,* 555 Kinderkamack Road, Oradell, NJ 07649-1517.

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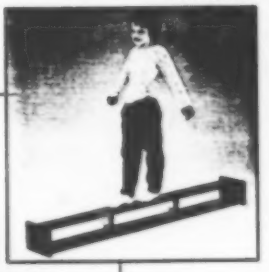

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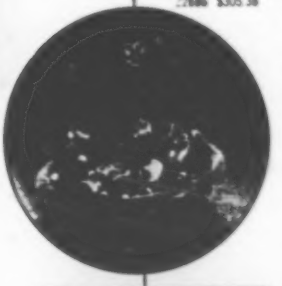

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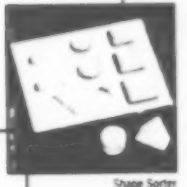

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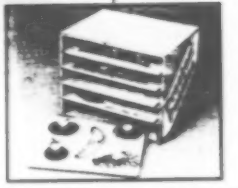

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EXCEPTIONAL PARENT
The Magazine for Families and Professionals
Parenting Your Child or Young Adult With a Disability
25th Anniversary

NOVEMBER 1996 VOL. 26, ISSUE 11

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Cover: Using the IntelliKeys keyboard and Hands-on-Concepts, a fully inclusive early-learning reading and math software program, Allison has fun with a counting rhyme on her Macintosh computer. Exceptional Parent wishes to thank IntelliTools for providing this month's cover photo.

BPA

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EDITOR'S DESK

14th Annual Technology Issue

In 1964, I was invited to participate in an introductory course on the use of computers in health-care research. As best I can recall, the course was sponsored by International Business Machines and took place near the Massachusetts Institute of Technology in Cambridge. At the time, I was directing a research project at a mental-health clinic for children.

STANLEY D. KLEIN, PH.D.

I have two powerful memories from that experience. First, we met in a large building more than three stories high. The computer itself took up most of the space in the building.

Second, I remember the demonstration of how this machine could assist researchers: A health-care colleague at a Boston hospital was doing research on breathing. Each day, an adult research subject came to the research laboratory for a physical examination, requiring various measures of breathing and other bodily functions. This took about an hour and the results were recorded with a pencil on a form. My often inaccurate memory says that there were less than twenty measurements that had to be recorded on the form. For the next seven hours, the research scientist labored over his electric calculator completing various mathematical formulas related to the measurements and then came up with some final numerical result. This same routine happened every day. Our course instructor that memorable day showed us how the form could be typed into the computer and a single research subject's measures then entered. Seconds later, what had previously taken a researcher seven hours to complete was done!

Twenty-one years later, in the October, 1985 EXCEPTIONAL PARENT, Jacquelyn Brand, a California parent, described how she and other parents, professionals and adults with disabilities had founded the Disabled Children's Computer Group (DCCG) in 1983. It was a model computer-access center for school-aged children with disabilities, their parents and teachers. By 1987, DCCG, in collaboration with Apple Computer, had become the Alliance for Technology Access (ATA). Today, the ATA is a vast nationwide network of centers providing hands-on direct assistance to children, adults, parents and professionals.

That is why we turned to the ATA to assist us in creating this annual technology issue. We extend our special thanks to Mary Lester and Russ Holland, as well as our fond best wishes to recently-retired Jacquelyn Brand. ATA members are still pioneers reaching out to teach us how to use the power of today's technology—far beyond anything demonstrated in that class in 1964!

Intrathecal Baclofen Therapy (ITB)

After a short introductory article in our August issue, we are now pleased to begin a special series of articles on ITB—the new therapy for spasticity which delivers medication directly to the spinal cord via an implanted device. The dosage of the medication is adjusted via a computer without removing the device from the abdomen. In this series, we will discuss ITB and its potential results, the actual procedures used and up-to-date information on the pros and cons of ITB. It seems fitting that Dr. A. Leland Albright, who helped develop the procedure, has contributed the first article. Stay tuned for more.

The New York Times

On Sunday, October 13, *The New York Times Business Section* featured an article entitled "A Plan for Parents of Disabled Children." Theresa Varnet, our "Future Planning" department columnist, and I both served as resource persons for the author of the article. The day following the article, I received a telephone call from a parent of a young adult with a life-long disability. This parent had never heard of EXCEPTIONAL PARENT magazine before! This reinforces the need to spread the word to all parents.

Forum '96

Thanks to all the wonderful children, parents and professionals who joined us in Anaheim at Forum '96 in October. We had a fine time and missed those who were unable to participate. For readers who missed Forum '96, we will share some photos in our next issue.

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For subscription and advertising information, see page 74.

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25th Anniversary
1971-1996

LETTERS

Paying for Physical Therapy

I am responding to "Managed Care," a letter in EXCEPTIONAL PARENT's July 1996 issue. C.M. from New York was having trouble getting her HMO to pay for her child's physical therapy. I am the office manager of a physical therapy clinic and I deal with insurance companies every day, trying to get them to pay for services. I also have a child with muscular dystrophy.

Most HMOs pay only for short-term physical therapy; two months is usually the limit. In other words, if you need more than two months' of physical therapy, you're out of luck. Fortunately, in Massachusetts, we have Commonhealth, a state-sponsored insurance plan for children with disabilities. It covers what primary insurance won't.

It is unfortunate that managed care is now a reality for many families. A doctor's prescription for physical therapy or any other service doesn't mean much anymore. Decisions regarding your medical care are no longer between you and your doctor. There are now nurse reviewers, managed care coordinators and review boards to make decisions about your child's health—people who have never met you or your child. Many have far less training and are far less qualified to make medical decisions than your doctor. Doctors receive financial incentives *not* to refer you or your child to specialists.

Hopefully, laws will be enacted to prevent insurance companies from denying care to their members and limiting services that are truly needed. Because only an act of Congress will accomplish this, we need to contact our federal and local legislators and urge them to pass this type of legislation.

L.P., Massachusetts

Saying Goodbye to Grampa

In the September 1995 issue, my letter, "Bringing Up Grampa," was published. We didn't have Grampa very long after that. He passed away on March 24. Our little granddaughter, who is autistic, is still grieving for him. He was her best friend, and she can't understand why he is gone.

Please don't sell these children short. They are capable of so many things, including love and grief. Just because children who are autistic seem to live in their own little world does not mean they don't know what's going on around them.

My granddaughter begged for her Grampa for two straight months, and cried for him every night. Then she got angry and kept saying, "Grampa be back." She went through all the stages of grieving.

I talked to her as I would to any other child. I told her the truth, that Grampa loved her very much, but that he died. Now she says, "Grampa dead" and her lips quiver, but she doesn't cry. She's trying very hard to adjust to her loss and it's amazing to watch her. I, myself, have not yet had the chance to grieve.

In two months, when the final adoption papers come through and she is mine, I will grieve. I will grieve because he is not here to help me celebrate and drink a toast to our little girl. I am so thankful to have this little girl in my life. What would I do without her?

S.T., Oregon

False Hopes and Technology

I read with interest the guest editorial "Imagine the Future" (November 1995). I gave special attention to the sidebar, "My Television Classroom," by Joseph Zlotek, a 10-year-old boy who utilized an ISDN (Integrated Services Digital Network) hook-up provided by Bell Atlantic to "attend" school from home while undergoing chemotherapy.

continued on page 6

You are:

1._____

2._____

3._____

4._____

5._____

6._____

7._____

8._____

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Circle #63

LETTERS

continued from page 5

In December 1995, my son had spinal surgery and was sent home to spend the next three to six months in a body cast and halo. I called the phone company to find out about ISDN in my area. They gave me an 800-number to call for more information. At that number, I got a sales pitch and another number to call. I got information in the mail. I even got an old computer from the school for my son to use. What I didn't get was anyone with a heart at the phone company. Nobody seemed interested in helping my son link up with his classmates at school—at least not for less than an enormous price tag.

All in all, I found both the editorial and the sidebar misleading. They implied that this technology can be had with the snap of a finger. Maybe that will be true in the future, but it's not true now, at least not in Vermont. Please be careful about what you print; false hope is cruel. I dared to "imagine the future"—what I saw was an abstraction.

L.K.Y., Vermont

Handicapped Parking

This letter is in response to B.S. ("Parking Problem," March 1996), who wrote of her frustration at the use of handicapped parking spaces by "able-bodied" people. I want to remind B.S. that many disabilities are invisible. For example, for a person with severe heart disease, a

continued on page 8

Tell us about...

...Your experience with non-special needs summer camps.

What obstacles did your child face and overcome? How did the camp respond to his or her needs?

Write to: *Readers Talk, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201)634-6570 (fax). A sampling of reader responses to this question will appear in a future issue.*

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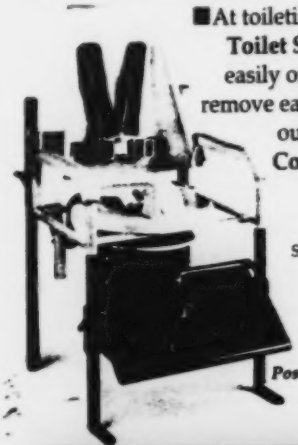

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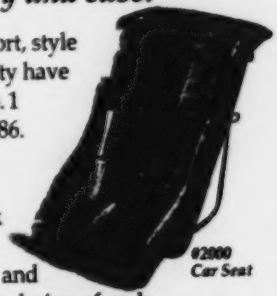

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space near the door may place a shopping trip just within the limitations of the person's energy reserves and pain tolerance. Other invisible disabilities may include arthritis, spinal conditions, leg amputations with prosthetic replacements, cancer and many others.

I strongly caution readers against jumping to conclusions about the "unauthorized" use of permits. They are not issued frivolously. In fact, I was denied a 30-day temporary permit for my child who needed to use a wheelchair for five months following surgery.

No one has the right to demand a stranger's medical history—not even if the stranger is an apparently healthy person using a handicapped parking space. I support stiff fines for able-bodied individuals who break the law, but common sense, empathy and just plain good manners should prevail.

D.W.R., Michigan

■ I am the parent of a child with a physical disability who uses a wheelchair. We have a permit to use handicapped parking areas. The Ohio Governor's Council on Disabilities provides parking lot security guards and people like me with "tickets" to be placed on the windshields of illegally parked cars.

These "tickets" are printed on bright yellow paper and contain a reminder that these parking spaces are provided for people whose physical disabilities require their use. They request future compliance with the law and consideration for others, but they also provide information on applying for a handicapped license plate should it be needed.

These "tickets" carry no fine, but they do bring attention to the violation. I keep a supply in my car and often place them on inappropriately parked vehicles.

B.A., Ohio

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax). Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication, but enables us to contact letter writers directly if necessary.

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SEARCH

Donohue Syndrome

Our daughter, Elizabeth, was born with a very rare syndrome called Donohue syndrome (Leprechaunism). Through our searches we have received many resources but nobody has been able to find another parent who has a child with the same disability.

Donohue syndrome is extremely rare, less than 58 cases have been reported. According to all of our research the last known case was in 1958. We would appreciate any information you can provide.

A.C. and N.C
Palm Coast, FL

Lethargy and Cyclic Vomiting

We would like to hear from anyone who can help us diagnose our 16-month-old girl or who knows of a child with similar presentation. She has moderate hypotonia, developmental delays, mild facial dysmorphic features and a small right hand and forearm, with syndactyly of the digits. She has also had severe esophageal reflux, for which she had a fundoplication done. She is fed through J-tube and given medications via G-tube.

Every ten to twelve days, Sarah experiences episodes of cyclic vomiting. The episodes generally last 4-6 days. During these times Sarah is lethargic and has little neurological reactions. She has also had two episodes of respiratory arrest.

Between these episodes, Sarah is an alert and socially responsive child who babbles, is responsive to auditory and visual stimuli, rolls and has begun to sit briefly independently when placed.

The following have been ruled out: familial dysautonomia, cystic fibrosis, Smith-Lemli-Opitz syndrome, Poland anomaly, non-ketotic hyperglycinemia, and any known metabolic disorder. Her pediatrician, gastroenterologist, neurologist and metabolic disease specialist are all puzzled.

N.C and B.C,
Brooklyn, NY

Craniosynostosis

My son, Joey, is twenty-one months old. He had a choroid plexus cyst in utero that disappeared by birth. He is thought to have had a brain hemorrhage shortly before or after birth. He was diagnosed with Craniosyn-ostosis at six months and had his first cranial reconstruction at seven months. A repeat procedure was done at sixteen months and was given a ventriculoperiteal shunt. A recent CT scan shows enlarged ventricles but there is no infection or malfunction of his shunt. He will soon undergo a shunt revision. At twenty months he was seen by an orthopedic surgeon for leg size discrepancy (both length and girth). X-Rays showed that his ocific nucleous in his left leg has not yet occified and is underdeveloped on the right.

I am interested in being connected with anyone with information on similar cases and would also appreciate any information available on treatment, support, advocacy, resources and referrals.

S.T.
Grandview, MO

Older children with hydrocephalus; arthrogryposis

Our family has recently adopted two ten-year-old children from Russia. Both were in orphanages and had received no treatment for their disabilities.

Michael has spina bifida and hydrocephalus. His spina bifida scar was revised and his cord untethered

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EXCEPTIONAL PARENT
The Magazine for Parents and Professionals

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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B. J. SEABURY, M.A., Director, Child Life Dept., Rhode Island Hospital, Providence, RI
HOWARD SHANE, Ph.D., Director, Communications Enhancement Center, Children's Hospital, Boston, MA
CAROL TINGEY, Ph.D., Parent, Psychologist, University of Utah Hospital, Salt Lake City, UT
HAROLD TURNER, D.D.S., Associate Professor, Retired, School of Graduate Dentistry, Boston University, Boston, MA

971

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GoodNites® mean Good Mornings™

Circle #72

972

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continued from page 10

in December 1995. This surgery went well and has even given him a little better bowel and bladder control. He walks well with ankle and foot orthoses. Our concern now is the hydrocephalus. Initially, the spina bifida clinic neurosurgeon said he didn't need a shunt, despite moderately enlarged ventricles, because he is stable and functioning well. He does occasionally vomit and complains rarely of headaches. Now, our local neurosurgeon and neurologist say he needs a shunt to preserve his remaining brain cells. We don't want to put Michael through an unnecessary surgery. We would like to talk with parents who have older children with hydrocephalus without shunts or who received their shunts when they were older.

Lena has arthrogryposis which affects all four extremities. She is doing well with toileting, dressing and feeding herself, but until recently she had never walked. She can walk approximately twenty feet with long leg braces and a walker contraption. She is in a wheelchair most of the time. We ordered a stroller from your magazine and it has been wonderful. But we are now wondering how much to push her to walk more. She is very content to sit in her wheelchair and let people push her. Do most kids with arthrogryposis walk? Has anyone had a child who learned to walk at age ten?

R.B., Iowa

EDITOR'S NOTE: *Be sure to contact the hydrocephalus groups listed on page 40 of our 1996 Resource Guide—the January issue—and the arthrogryposis group listed on page 29. For a copy of the Resource Guide, contact EXCEPTIONAL PARENT LIBRARY: 800-535-1910.*

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax).For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt 37, P.O. Box 8923, New Fairfield, CT 06812; (800) 999-6673; (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513; (800) 651-1151 (V/TTY) or (706) 632-8830 (Fax).

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Circle #51 973

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RESPOND

Pachygyria

K.A. (September, 1996) has a two-year-old son diagnosed with pachygyria, a brain disorder. K.A. was looking for other parents with children of the same condition.

We, too, have a son that has Pachygyria. He is five years old. He was diagnosed at three weeks of age and we were told that his prognosis was poor. We were devastated to say the least and not knowing what the future held made things worse. We were actually told not to expect Nathan to progress mentally much past the age of three weeks.

Even though today Nathan still cannot walk or talk (although we do get "mom," "mom-mom" and an occasional "da" from him), he has progressed so very much more than any of his doctors had ever expected. he is on the verge of crawling but for now he rolls wherever he wants to go, usually to play with his toys or to watch the fish in the tank we have set up for him. He learned to drink by himself from a leak proof sipper cup and has recently learned to finger feed himself. He sits up on his knees without support and reached up to things and tries to pull up. Nathan's strongest attribute, however, is his ability to show us unconditional love.

Nathan seems to learn things at his own pace. If I had any advice to give it would be don't expect too much too soon. Enjoy him and love him just the way he is now because he truly is a gift from God. If you haven't already you should get him involved with some type of physical, occupational and speech therapies. Our son receives most of his through the Headstart program in the local school system and has benefited very much from it.

C.F.
North Dakota

Chromosome Anomaly

M.B. and K.B. (September, 1996) have a daughter who has a chromosome anomaly called 13q-, a partial deletion of the long arm of the 13th chromosome. She has cerebral palsy, cortical visual impairment and moderate to severe hearing loss. M.B. and K.B. were looking for parents of children with similar disabilities.

I have a three-year-old daughter who was born with a seizure disorder and developmental delay. In the last year, we discovered that she has cortical visual impairment. Morghan is rapidly improving every day, and with the help of a counselor from TIPS (Tennessee Infant Parent Services, for children under the age of three who have vision or hearing loss), is coping well with her vision problems. As you are probably aware, it is hard to find much information on cortical vision impairment. Your child will need

continued on page 19

NEW! The kid-T-REX tm, a super light foldable stroller, that provides padded therapeutic positioning, many years of growth and adaptability.
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Circle #55

975

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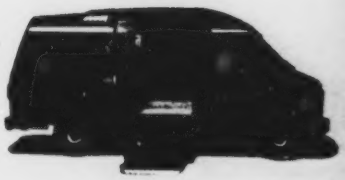
Lift-A-Way® Lift - the original design that has provided dependable mobility for over 30 years.



Swing-A-Way® Lift - this innovative design offers the widest clear-path access to the side door in the industry.

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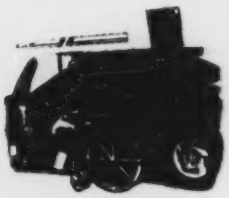

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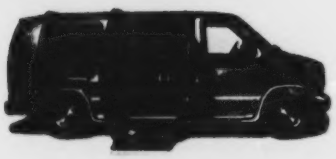

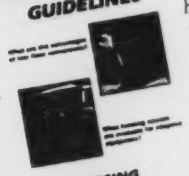

To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

976

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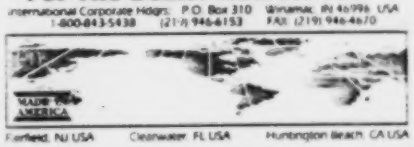

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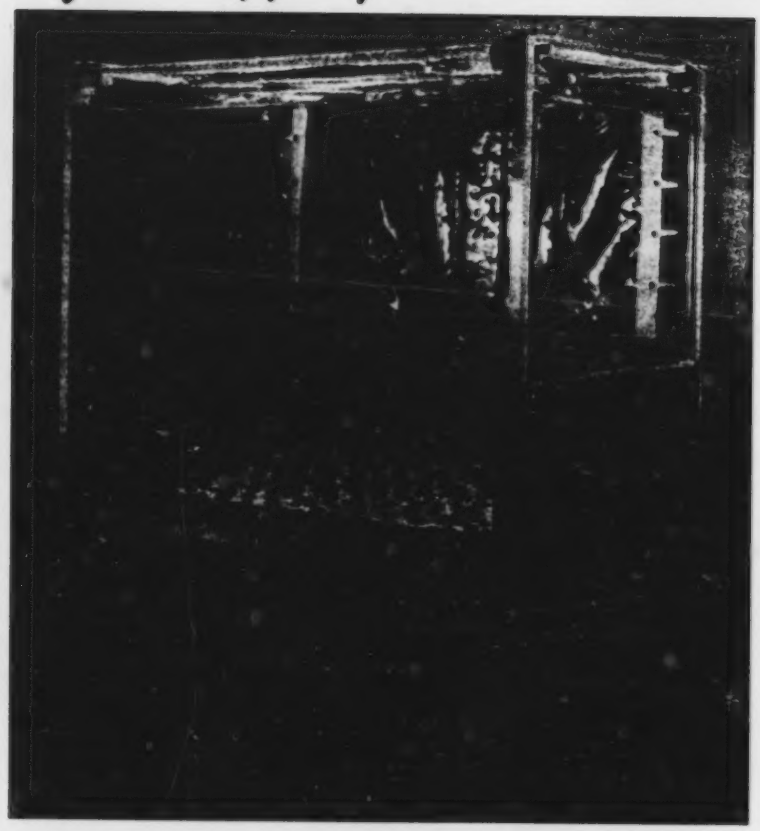

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1-800-USE-HARD

continued from page 14

intense therapy and stimulation to deal with or even overcome this disease. However, our counselor, Dena, has resources to a large communication network and found many helpful articles for us.

Prior to the age of three, she attended LesPasses Child Care center in Memphis every day. This was the best program we could have ever found. The center is state funded but it is also helped by public fund-raisers in the community. The teachers are specially trained to work with children with disabilities and they have a full staff of full- time physical, occupational and speech therapists. TIPS is available all over Tennessee. Their Memphis phone number is (901) 678-3501.

R.K
Memphis, TN

Spastic Quadriplegia

I am the parent of a 13-year-old boy with spastic quadriplegia. We started working on toilet training with Brian six years ago. It has had its ups and downs. Brian uses the Rifton potty chair because he also needs maximum support. I have one at home and he has one in a private bathroom at school. When we travel Brian can use a urinal with assistance. My husband has also made a toilet seat with straps for a regular toilet. He made it out of PVC pipe and it has worked out pretty well for us.

As far as toilet training goes, we try to take Brian to the toilet about every two hours. He also usually moves his bowels the same time every day. He does know when he needs to go and he will let us know. We have found that if he is involved in something that requires a lot of work on his part he may have an accident. We have accepted this as part of Brian and take it in stride. I don't think he will ever be totally continent due to his tone. But if he is incontinent he will let us know so we can change him. Because of school and the embarrassment of accidents, I put Huggies PullUps or Goodnites on him. It also saves on the wash!!

H.M.
Franklin, MA

MMR Vaccine in Utero

L.R. (May 1996) is the mother of seventeen-month old Joshua, who has cerebral palsy, microcephaly, deafness, seizures and other disabilities. L.R. believes Joshua's disabilities resulted from the measles, mumps and rubella (MMR) vaccine she was given very early in her pregnancy, before she knew she was pregnant. L.R. was interested in finding families of similar children.

I, too, received the MMR vaccine as a requirement for nursing school. I did not know that I was one-to-two weeks pregnant at the time. My son, Tyler, now five, has cerebral palsy, epilepsy, autism, a hearing impairment and several other problems.

M.R., Alabama

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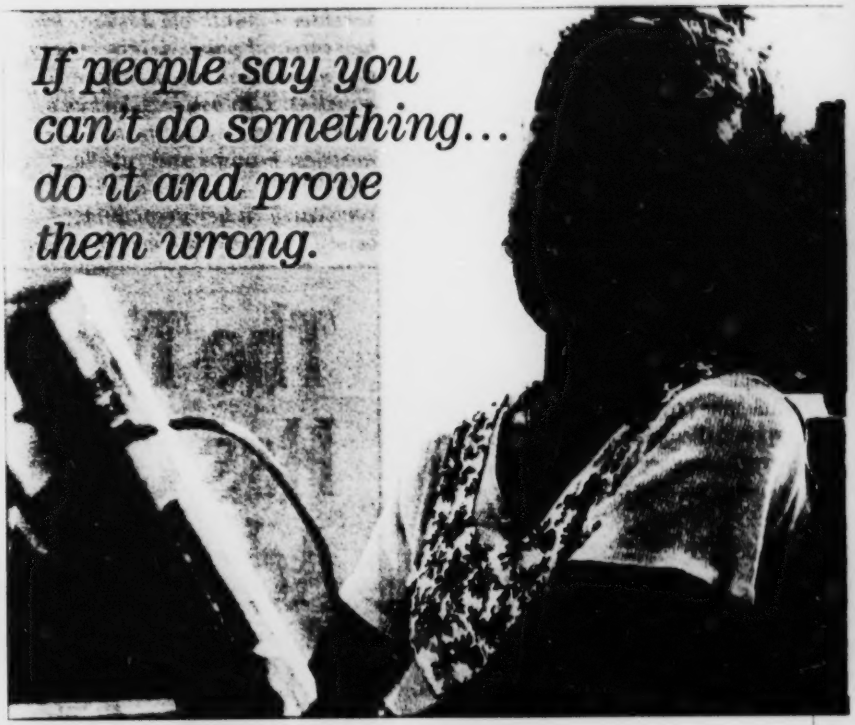
March of Dimes

PFC PLANNED FINANCIAL CONCEPTS

Circle #86

Role Models



Beth Anne Luciani

I was born and raised in Monessen, Pennsylvania. My mom tells me when I was born the umbilical cord was wrapped around my throat and cut off oxygen to my brain. When I was four days old I had grand mall seizures. I was treated with medication and was checked monthly by the doctor. When I wasn't sitting by six months and would become very stiff when I cried, my mom was pretty sure there was something wrong with me.

My parents found out I had cerebral palsy when I was nine months old. The doctor told my mom that I would probably have a limp and poor handwriting! He never thought I was going to be this seriously involved.

But my parents did what they had to do for me and have accepted my disability. They just told me that I had cerebral palsy and I would probably never be able to walk or talk, but I had a great mind and I could learn like any other kid.

They got used to my inability to speak. I use eye gaze to talk to them. My mom can understand me the best; we have a system to talk to each other. Nobody understands how we do it.

My parents spoil me rotten—but they treat me like a normal teenager. I am lucky because I have wonderful parents who look at me like a normal kid. I love my parents very much.

Monessen is a small town of approximately 10,000 people. I live with my mother and father, my dog, Cinnamon, and my three cats, Misty, Beauty and Beast. Since we live in a town, I rely on our family van to get around in the community. Our town is extremely hilly and pushing my wheelchair or getting around in my power chair would not be very feasible.

I enjoy shopping, going to the movies, visiting family and friends and especially doing things with my eighteen-month-old goddaughter, Haley. She is a joy to my life and loves me just the way I am. Her favorite thing to play with when she visits me is my wheelchair, and she loves to watch me use my DynaVox.

School is my second home

I have been going to the Day School at the Rehabilitation Institute of Pittsburgh since I was five. It's an approved, private placement school, so all of the kids there have some sort of disability. It makes it very easy to make friends and be treated alike. No one is any more special or different than you are. I like going to school there very much.

I started out in a class that was "low functioning," and after two weeks I was moved to a higher class. All through school I have amazed teachers. Right now I am in the highest academic class in my school. What held me back from going at the pace of a normal kid were my therapies. My therapies—speech, physical and occupational—were out of the classroom. It was all good, though, because it helped me.

People think I am absolutely crazy because I love school. School is like my second home. Summers are very boring for me! I can't wait to go to school and see my friends and learn. I know I am a strange kid. I have always had great relationships with my teachers because I am bright and I can talk to them about normal things. Though there are kids ranging from the ages of two to twenty-one at my school, I make more teacher and adult friends because I can talk to them easier and they understand my problems better than the kids. I've never had a real social life with friends my own age. I've

continued on page 22

979

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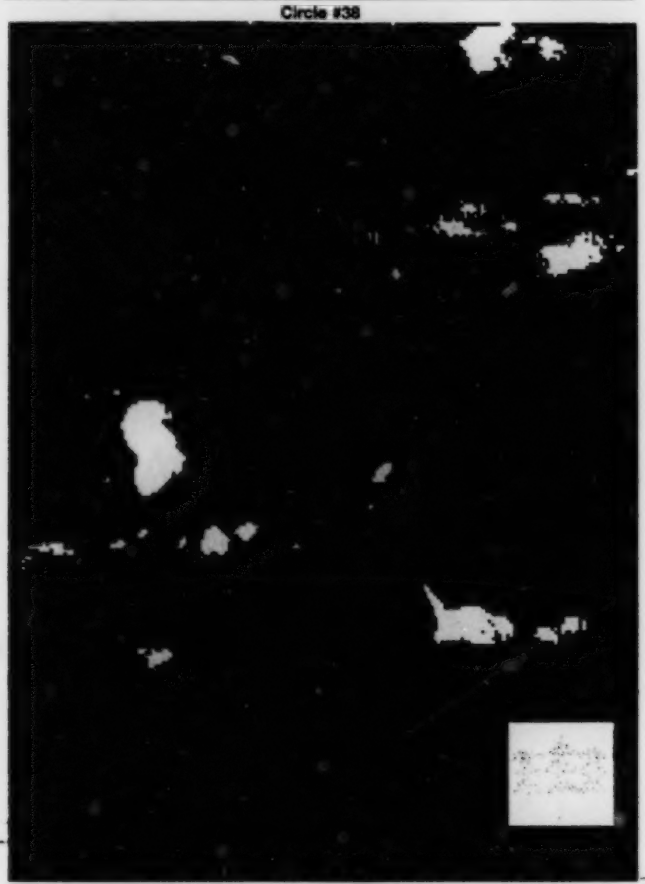
Circle #38



Circle #29

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always had adult friends that I am close to.

And I'm very close to my cousin. She is four years older than me and we were like sisters growing up. On my thirteenth birthday, she and her boyfriend took me to Chi Chi's for dinner!!! I also am very close to my former physical therapist. She takes me out a couple times a year and we go to the movies or swimming.

I have not had a boy-girl date yet; however, our school sponsors a prom and I have attended the past two years. Our proms do not encourage couples attending, rather everyone comes by themselves and has fun as a group. The senior high has a student council and this is the third year I have been on it. We arrange and sponsor spirit days, dances, proms and fund raisers. Whenever we need a sign or a banner for an event, I am the one who makes it. I also belong to the Chess Club and participate in our Jump Rope for Heart program.

The Year 2000

When I was a little girl and all the way up until I was about twelve, I wanted to be a ballerina. Then I realized I couldn't be a ballerina and so I wanted to be a ballet choreographer. But now I want to be a computer programmer.

I will graduate from high school in the year 2000, at the age of twenty-one. I plan to go on to a four-year college, either the University of Pittsburgh or California University of Pennsylvania. I do not know what assistance I will need when I go to college—whether I can get an aide or not. I do know that if I cannot get an aide, my mother will either go to school with me or hire an aide for me. She will help me as much as possible.

I would like to study computer programming. I realize my math skills may not be enough from high school, so I may have to go to a community college first to bring my math skills up. I have been attending a vocational school in our area for computer science and should have completed three years at this school by the time I graduate from high school. At the end of the three years, they might get me a part-time job while I am still in school.

Going to vocational school has been a real eye-opening experience for me and my family. I have had many problems with the teachers accepting me and my DynaVox. At one point, I simply left the room in frustration and went to the Supervisor to vent my anger. Things are getting better this year, but without the help of my Transition Coordinator from the Rehabilitation Institute, I think my mom and I would have gone crazy!!

My Suggestions

Let your child be as normal as possible. Don't make him or her wear out of style clothes and other things like that because they will feel more different from society than they already feel. Don't hang onto them; let them go out

981

with friends if they can. I think most parents don't realize how much going out means to a child with disabilities. I am fortunate that I have a couple of adult friends without disabilities who take me out and that my parents allow me to go out with them.

I feel I am fortunate because I can learn like a normal kid. But I don't think it is fair that I have to fight for my rights everywhere I go because I have a disability.

Treat people with a disabilities like any other person. Just because we have a disability doesn't mean we can't work or understand what you are saying. I always tell people I am just a normal kid, except my body doesn't work right. I think many people think of people like me as dummies. When you meet a person with a disability, just talk to them and treat them like a normal person.

Don't be depressed about your disability. You are a wonderful person no matter what. If people stare at you, just stare back. If people say you can't do something because you are disabled, just do it and prove them wrong. The last thing that I can't stress enough is stand up for your rights. If more people stand up for what they need, then more people will know what we need. **EP**

Thanks to Sentient Systems Technology, Inc. for nominating Beth Anne to be this month's role model.

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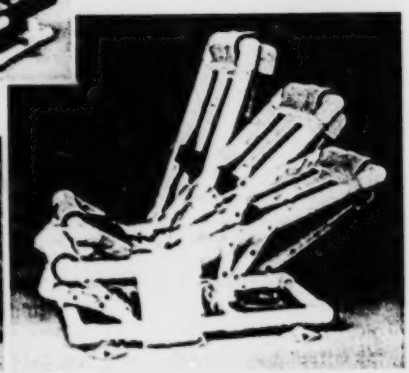

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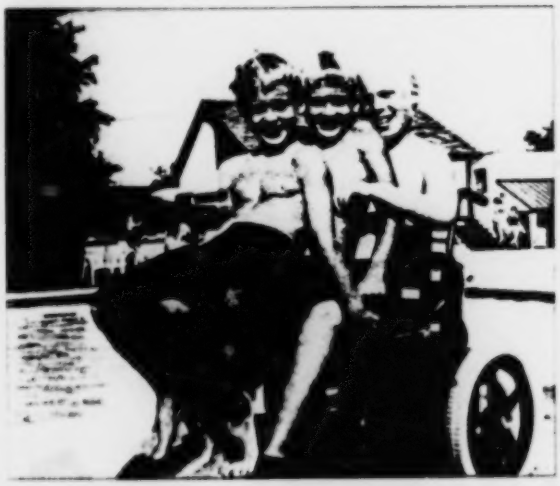
Circle #42

Familiar Faces

Hair up and ready for anything, **Eleanor Ann Faber**, 3, grins from ear-to-ear as she poses for the camera with her mother, Lisa, who describes Eleanor as "a sweet and loving child." Eleanor, who has osteogenesis imperfecta as well as developmental delays, lives in Elmhurst, Illinois, and loves going to the zoo and playing with her dolls.



A day at the pool is even more fun with friends! Ten-year-old **Andrew Chrisman** (far right) loves giving buddies Ryan and Chad Drzewiecki rides on his wheelchair. Andrew, who has cerebral palsy, loves to swim and is very active around the swimming pool. He lives in Lebanon, Pennsylvania, with his mother and father.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517 (Sorry, photos cannot be returned). On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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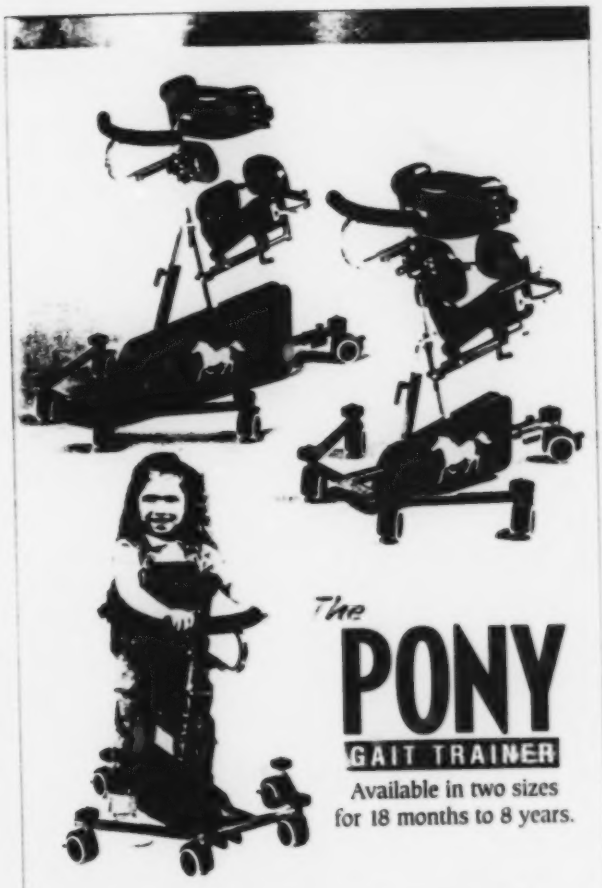
Getting in the last few days of summer, **Daniel Hayden Barnhart**, 2, sits in his beach chair and soaks up some rays. Daniel was born three months premature and has spastic quadreplegia cerebral palsy. He loves to read books, play with his cousins and eat spaghetti and ice cream. He lives in Grottoes, Virginia with his parents, Lillian and Chip.

Christina Preston, 4, enjoys a picnic with her newly adopted brother, **Aaron**, who is eight months old. Chrissy, who has Down syndrome and leukemia in remission, likes to help with the vacuum cleaner and wash her hair with baby wipes. Aaron is blind due to severe micropthalmia. They live in Ambler, Pennsylvania.



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Circle #61

Active Accessibility

Learning a lot to empower all people

Personal computers are often—and rightly—seen as conveying increased freedom and independence to children and adults with disabilities. They can, and have, made it easier for people with visual impairments to read, for those with mobility impairments to write and for those with speech difficulties to speak. In doing so, computers have also aided in the employment of people with disabilities.

In spite of the difference they can make in a person's ability to work, learn and play, however, a personal computer is a "work in progress." It can easily become irrelevant if the user can't manipulate the newest standard personal-computer keyboard or mouse, see the screen or hear the sound from its speakers. Personal computers, and the software that runs on it, must be accessible.

So, what's Microsoft doing about insuring that personal computers are accessible to people with disabilities?

Accessible program design

The cornerstone of Microsoft's accessibility/disability efforts is its Corporate Policy Statement. It outlines the responsibilities of each employee to insure, during all phases of product planning, development and support, that the company addresses the needs of people with disabilities.

The first example of this commitment was the inclusion of Accessibility Options in Windows '95. These built-in utilities for people with disabilities were developed in cooperation with users who have disabilities, organizations representing people with disabilities, workers in the rehabilitation field, software and hardware manufacturers and the Trace Research and Development Center at the University of Wisconsin-Madison, using research funded by the National Institute on Disability and Rehabilitation Research (NIDRR).

Inclusion of the Accessibility Options in Windows '95 was an important milestone. It documented Microsoft's commitment to insuring that, over time, its products become more accessible for people with disabilities. In addition, including access utilities in such a popular operating system let the entire personal-computer industry know that a new technology-related age had arrived for people with disabilities. Everyone needs to use the latest-and-greatest. Yes. Everyone.

For many people with disabilities, though, the rapid and widespread customer-driven adoption of graphical user interfaces has brought unintended concerns or hardships. It has been difficult for software vendors to translate the graphical user interfaces into a format accessible for people with disabilities. The responsibility to aid blind users in the transition to graphical-based software is shared by software developers throughout the industry, users with disabilities and the advocacy organizations that represent them.

With this in mind, Microsoft has made the commitment to insure that accessible product design will no longer be an afterthought and that the development of accessibility aids will no longer lag behind personal-computer developments. For example, Internet Explorer 3.0, a product used to access the Internet, includes features that make it the most accessible commercial browser available. More importantly, Microsoft's Designed for Windows NT and Windows '95 Logo Program includes recommendations that software developers must address in order to use the Windows logo on their products. Accessible design will no longer be a specialty attended to by a few while needed by so many.

Accessibility aids

What about development of accessibility aids? Fact of the matter is, the ability of people with disabilities to use state-of-the-art personal-computer technology would continue to lag behind if the fundamental problem prohibiting access was not solved. How do operating systems, software applications and accessibility aids communicate and interact with one another? What can be done to insure that a person with a disability does not have to worry about having access to any hardware or software product?

Microsoft's proposed solution to the problem of how to insure accessibility aids will always work is Active Accessibility. Active Accessibility is a set of tools software manufacturers can use to make their products accessible. Active Accessibility will be built-in to Windows 95 and Windows NT, thus making the work of accessibility-aid manufacturers much easier. It is not a product that you will buy. Rather, it is something that you look for in a product, much as you look at a car to insure it is safe to drive.

Personal computers are empowering people with disabilities. Everyday. As the technology evolves, more and more people with disabilities will be able to use personal computers. Easily. Out of the box. With no additional, incredible expense. Exactly as it should be. On the horizon, it looks like the needs of people with disabilities will finally be able to keep up with the evolution of the personal computer. That's the way it was supposed to be from the start. The personal-computer industry had a lot to learn. **EP**

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

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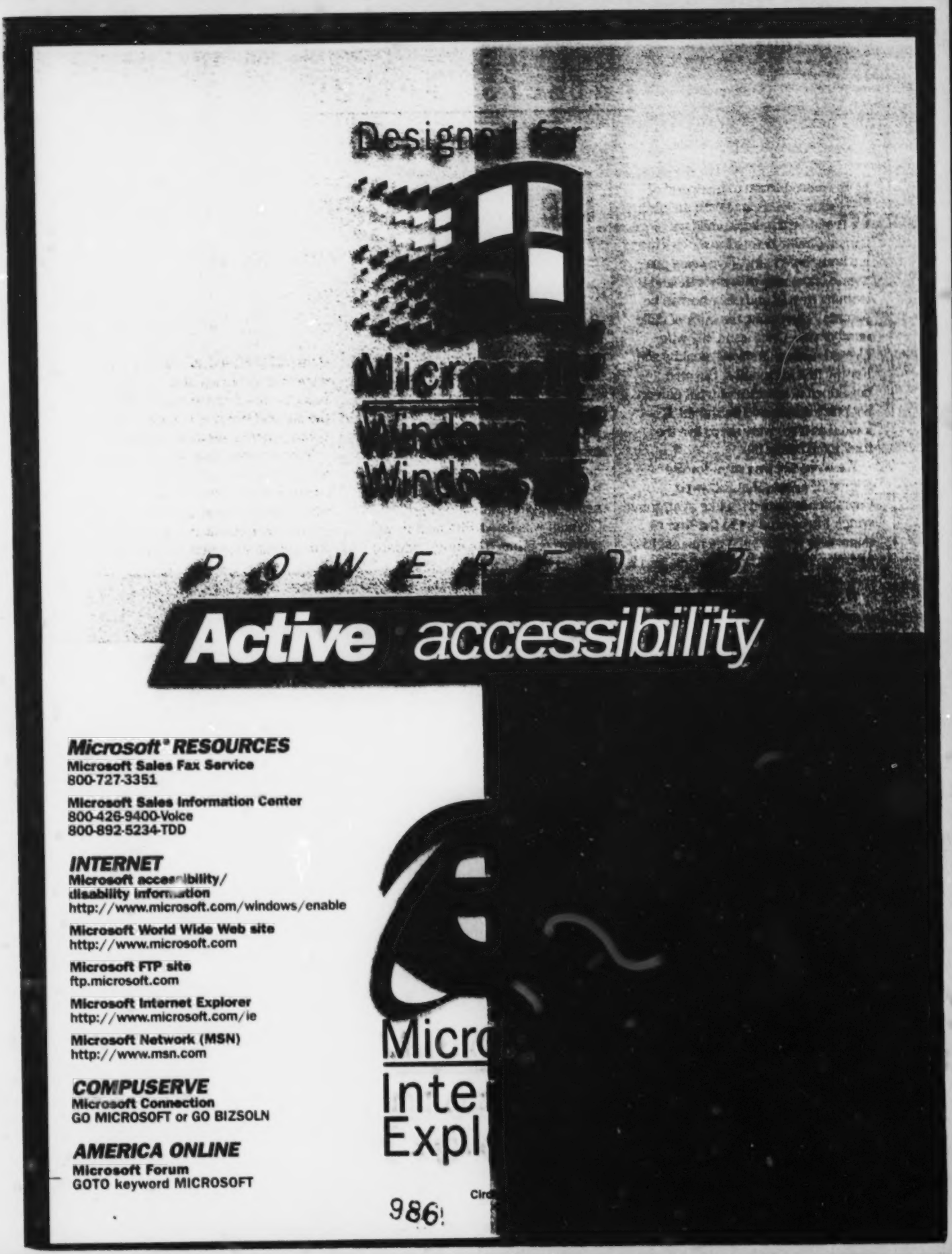
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The Lone Father

Dad learns many new skills, especially advocacy.

By Wilbur Hawke

My introduction to the world of fatherhood came with the birth of a healthy male child we named Conan, before the movies made it a household name. Five years progressed normally with my wife and I learning by trial and error how to be parents. Then came the birth of child number two. Once again, my wife blessed me with a strong, healthy son. For the first six months, Cayman developed in advance of what parenting publications said he should. It looked as if we were set to live the traditional family life.

We were not prepared for the course of events that followed. Cayman developed flu-like symptoms which introduced us to the first of many new terms, such as meningitis, hydrocephalus, shunt, ventricle and a host of others.

The struggle to save our son's life is even now, eleven years later, painful to recall. The one thing I can never forget about that time was my bargain with God. If He would let Cayman live, I would take care of him, knowing the effects of his diseases could be devastating. As I watched Cayman lose half his body weight, I never lost hope. Finally, God answered my prayers. Now I had to keep my end of the bargain.

The care Cayman needed meant one of us would have to stay at home. My wife's income was greater than mine, so the choice was not difficult. This was a new experience for me. I learned to change diapers, cook, clean, and do laundry. I will admit there were times my family wore pink underwear while I was learning to separate the wash.

Our doctor said it would be impossible to determine the extent of damage until Cayman was older, then referred us to an early intervention specialist. We found ourselves at the beginning of a very long road to re-teach Cayman all the things he had done so quickly before. Once again new terms—occupational therapy, physical and speech therapy—all became commonplace in our home.

The early intervention therapy continued and Cayman made steady progress. But when he turned three, testing revealed another blow to our child. Cayman had lost 80 percent of his hearing and another term—deafness—entered our vocabulary. Cayman was fitted with hearing aids and we continued to move forward.

Wilbur Hawke says it's painful to recall the struggle to save his son Cayman's (left) life, but he never lost hope. Surrounded by a sea of mothers, he learned to advocate for his child.

I began to feel like the "Stranger in a Strange Land." Sitting in the offices of physicians and therapists, I was the only Dad to be seen. I did not know enough about my child's history to answer questions, and I gained a better understanding of why professionals would turn to my wife for information about Cayman. I developed a healthy respect for her ability to cope so comfortably with issues that for me created crisis situations. As time passed, I would acquire these skills myself, and become more self-confident in my ability to perform the role I had accepted. With the support of my very patient wife, I continued to make steady progress.

The next step came when Cayman left the protective pre-kindergarten environment and went to public school. Since Conan had already been to the local elementary school, it was only logical to me that Cayman should do the same. We rejected ideas to send him to a special school in a neighboring county or another state. Once again, I found myself submerged in an environment alien to most fathers—the public school system.

Cayman went to a regular class and all seemed fine. He was getting some extra help from a special education teacher and a speech therapist. We attended our annual I.E.P. (Individualized Education Plan) meeting, where we listened to many

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professionals say things we didn't understand, but left feeling secure they knew what was best.

By the end of second grade, Cayman was beginning to develop a severe gap in reading and language development. We attended another meeting and were told Cayman should enroll in a neighboring county's program for deaf children. The bus ride would only be two hours a day, and Cayman would receive the services he so desperately needed. Still trusting their opinion, we consented.

The bus ride was two hours *one way*!! The pain we experienced when we placed Cayman on the bus each morning with a pillow and blanket, then waiting an extra two hours for our child to return each night cannot be put into words. But the professionals we once trusted did not listen to our concerns.

Another chapter in my life began—advocacy—and I again entered an arena dominated by mothers. My vocabulary expanded to include these terms—Free Appropriate Public Education, Least Restrictive Environment, Section 504, and I.D.E.A. (Individuals with Disabilities Education Act). The search for information began with my wife visiting the library while I searched the yellow pages. We found an organization called the Advocacy Center for Persons with Disabilities. They informed us of rights granted children with disabilities that had not been mentioned by the local school district. We also learned of a group called the Family Network on Disabilities of Florida, a Parent Training and Information Center.

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Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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The State of the Alliance

Telecommunications creates a virtual community.

by Russ Holland

Since its inception in 1987, the Alliance for Technology Access has worked to redefine human potential through the empowering application of technology for children and adults with disabilities. During that time, there have been tremendous changes in the technological, social, political and economic environments in which we are working. The Alliance continues to evolve with those changes. The evolution is a dynamic one, as 40 centers and 70 vendor and development partners work together to enhance what has proven to be an exceptionally successful model, which will be even more effective in the next century.

One of the most dramatic evolutions in the field has been in the use of telecommunications. In a time when the assistive-technology field was very young, the Alliance pioneered the use of telecommunications to tie our virtual community together and share our collective experience and expertise with every consumer contacting one of the Alliance Centers.

What was once for us a vital but uncommon mode of communication is now mainstream, and participation in that mainstream now requires that we work to ensure that every consumer and family can access it independently.

Information once very difficult to come by is now more readily available on the world wide web, through our own presence there (http://marin.org/npo/ata/) and through links to myriad other resources, both within and outside the Alliance. Our emphasis on facilitation of access to these resources is evident and continues the evolution of our model—not as keepers of information, but conduits to it. We encourage all readers to gain access to telecommunications and to work with us in an advocacy and educational effort to keep this critical media accessible for everyone.

The Alliance is constantly working to strengthen the collaborations and partnerships that make up our community, while looking at ways to invite new partners into the effort to increase our success in accomplishing our mission. We are working with vendor partners to impact on the next generation of products, promoting acceptance of the concept of Universal Design, in which all products are designed from the bottom up to be usable by the broadest possible spectrum of consumers, rather than needing to be made "accessible."

We are, with this November Technology issue, also expanding on our long-term relationship with EXCEPTIONAL PARENT. Having contributed to the annual technology issue for a number of years, we will now be providing information and connections to assistive-technology resources in every issue. We are excited about this new outreach opportunity, which fits both our mission and EXCEPTIONAL PARENT's

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Talkin' Tech

KIDS COMMUNICATE THROUGH ADAPTIVE TECHNOLOGY

A Special Tomato

by Carrie Bergeron

My mom and dad had four children. The first three were healthy. Then I came along, a Down syndrome baby with a difference. I had a hole in my heart, a rip in my heart valve, jaundice, a big tongue and a wobbling head. As I got older, I also realized that I am a slow learner. One day, it was bothering me that I was having a hard time doing my schoolwork. I told my dad about this problem. He shared a story about when he was out in his garden picking tomatoes, the year I was born.

Every year my Dad loves to plant tomatoes. At harvest time there were Beefsteak tomatoes on a bush. When he saw a differently shaped tomato, it got his attention. It had a large, smooth, bright red enlarged side that made my dad want to pick it up and study the bump. It was so unique and looked appetizing. At supper that tomato was just as delicious and juicy as the others.

The point of this article is that even though I'm different, my family and friends love me even more and want to help me when I need it. My dad tells me that even though I have more learning difficulties than my brother and sisters, my lovable, outgoing personality and strong character make me just as special as they are. I guess I am a special "tomato" on the Bergeron bush!

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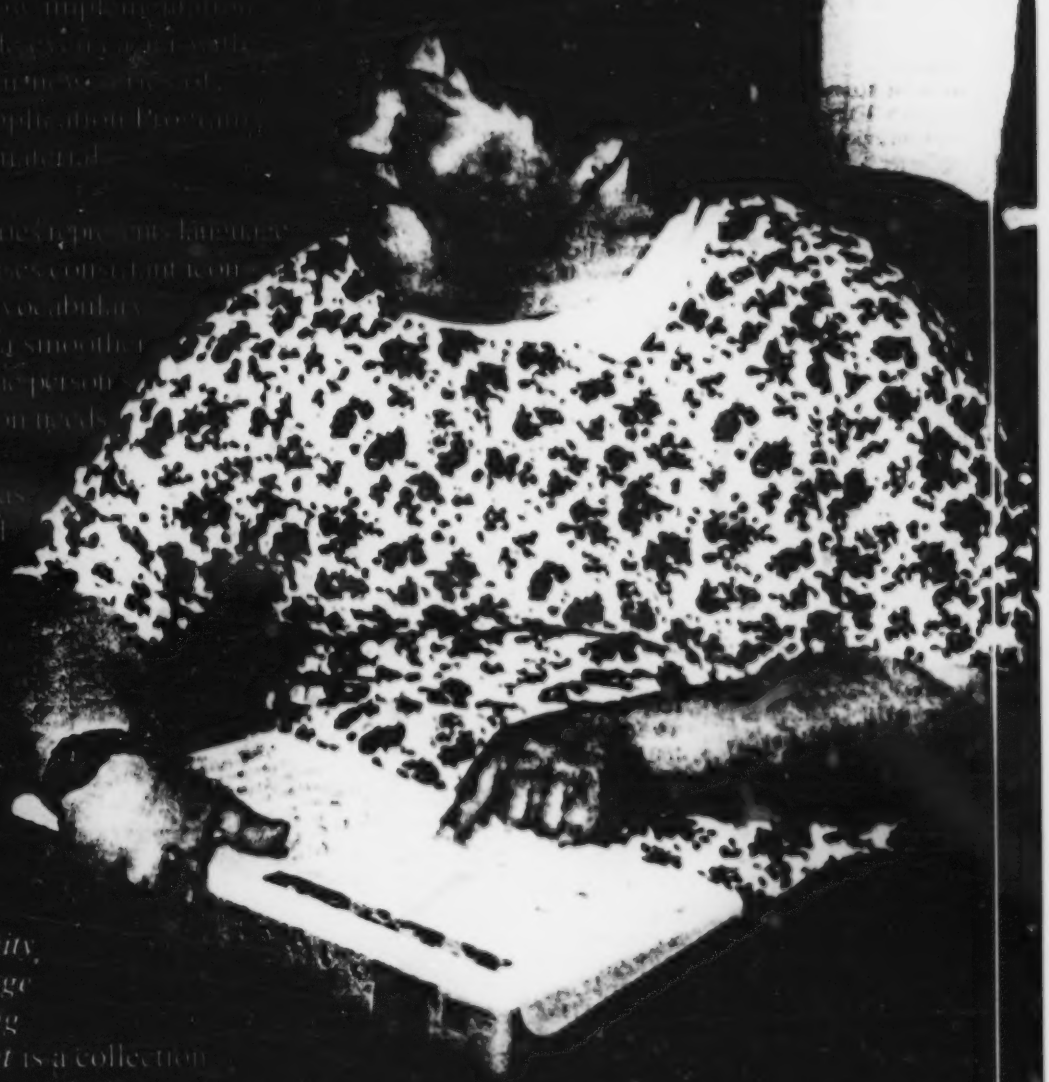

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continued from page 30

commitment to increased and ongoing assistive technology resources.

As the environments in which we work continue to evolve, we invite everyone to collaborate with us to provide access to these technologies for all who wish to use them, increasing their independence and participation in mainstream society. We are looking at how best to build our Alliance community and work with more of those who share our philosophy and goals. We look forward to hearing from parents, children and professionals with feedback or for information about participation or membership options.

For more information, contact the Alliance office at (415) 455-4575, or e-mail them at atainfo@aol.com

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All staff members at CECC—from nurses to teachers to administrators to groundskeepers—extend extraordinary care to children everyday, in countless small ways. They know who enjoys hustle and bustle, who prefers peace and quiet. They remember to open a window to let in a spring breeze, or to choose flowers both for appearance and fragrance. Every wheelchair has a handwritten card on the back, alerting staff to that resident's likes and dislikes.

Located in Groton, Mass., CECC admits and offers short-term and long-term

care to children from birth to age 22. All services are tailored to the needs of each child and family. In addition to receiving skilled nursing care, children participate in a school program, where an integrated curriculum matches activities with abilities.

Through the "Into the Community" program, CECC residents mix with the neighboring community and members of the community join activities at CECC. Several CECC residents attend nearby public schools for a few hours a week accompanied by a CECC staff member.

A subsidiary of Children's Medical Center, CECC is housed in a cheerful, two-story building in a residential neighborhood. The grounds include a large outdoor play area, gardens, and a swimming pool, allowing residents and visitors to enjoy a variety of outdoor activities.

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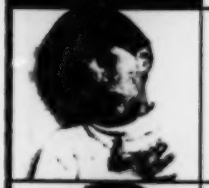
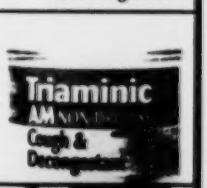
 NASAL CONGESTION AND CHEST CONGESTION	Triaminic EXPECTORANT Chest & Head Congestion
NASAL CONGESTION AND DAYTIME COUGH	 Triaminic AM Cough & Decongestant
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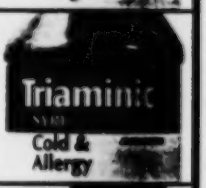
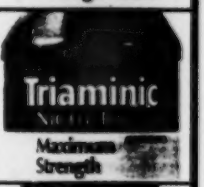
NASAL CONGESTION, RUNNY NOSE AND SNEEZING	 Triaminic SYRUP Cold & Allergy
NASAL CONGESTION, SORE THROAT, FEVER AND COUGHING	Triaminic SORE THROAT Throat Pain & Cough
NASAL CONGESTION, NIGHT TIME COUGHING, SNEEZING AND RUNNY NOSE	 Triaminic NIGHT TIME Maximum Strength
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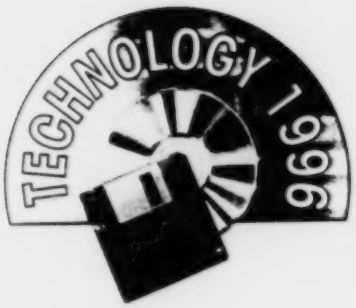

Connecting to the World

Information age offers many advantages.

by Mary Lester

Andy and Jonathan are two boys in a school in Australia for children who are deaf. Through a commercial online service connected to the Internet, the boys posted a message asking for pen pals.

Joshua and Caleb are brothers, ages 12 and 10, who have no disabilities and who live in Kentucky. Their father, an Internet user, saw the message and had them write Andy and Jonathan.

Now the four boys are electronic pen-pals. They write about Nintendo games, basketball, school, their homes, their friends and the weather, which is especially interesting because it's winter in Australia when it's summer in Kentucky.

It was a month before Joshua and Caleb knew that Andy and Jonathan were completely deaf. The boys think it's great that they can't tell anything about race, size, age, appearance, or disability by sending and reading e-mail, but that they can share the secrets of Nintendo and have a lot of fun getting to know each other. Andy and Jonathan hope to come to the United States one day. Joshua and Caleb are finding someone to teach them sign language.

Bringing people together

Technology has the power to bring people together by providing them with the ability to interact and communicate in new ways. But the new frontier of telecommunications, sometimes called the information superhighway, offers so much more—the ability to access databases of information stored on another computer, download files and make reservations are only some of the things you can do on the Internet.

But how could someone with a disability take advantage of this technology? In the same ways that anybody would:

- Accessing vast databases of information beyond their geographic limits;
- Tapping on-line educational programs;
- Sending and receiving electronic mail to share interests with others;
- Telecommuting in order to work from home;
- Operating a home-based business.

The pluses

Certain aspects of telecommunications are particularly well-suited for people with disabilities because of the access they provide. Users bring information right into their home and use assistive technology to read or edit it. Messages can be written with any sort of input device and the writer can take as much time as necessary. Because the person on the receiving end reads the message at his or her leisure, the user's disability is neither apparent nor relevant to the process.

Through telecommunications, users can take advantage of a wide range of services without leaving their home, such as obtaining up-to-date information on computer games and music groups. Libraries that are otherwise inaccessible because of transportation and architectural barriers or difficulty with manipulating books or reading print are now just a mouse click away. One can even

Talkin' Tech

KIDS COMMUNICATE THROUGH ADAPTIVE TECHNOLOGY

Doing it Myself

by John Fodi

Did you ever wonder how someone with cerebral palsy worked a computer? I have a special laptop computer that has a special head switch that hooks onto my chair.

My head switch is for typing because I can't use my hands. The computer has a special program that puts a block of the letters and numbers onto the monitor.

The few things that are good about it are it improves my typing, it lets me do my own writing and I can do it myself. The bad things about it are it takes a long time to hook it all up, it's hard work, it's frustrating and it's slow and takes a long time to type words out.

I think it helps cerebral palsy kids like me write without having any help but they need a better program because this one takes too long.

995

"You've Got Mail"! by Venessa Couveau

For the first time in my life, I am totally independent. I am doing what every other teenager is doing—talking on the phone. The great thing is there's no one looking over my shoulder! Being online is exciting. I love to hear the voice of America Online say, 'You've got mail!'

I talk to all kinds of people on the Internet. Now, I can write my feelings down and e-mail them to my best friend, who just got online. This is important because she just started college and I don't see her as often as I would like, especially when I am used to seeing her every day and chatting. E-mail helps ease the pain.

There's a lot of stuff waiting to be explored online. I almost ordered flowers for my sister, but mom caught me in the act! Sometimes I use chat rooms to talk to people online. You can download all kinds of research. You can even download games.

Recently, I discovered how to use my modem to access the telephone relay service (TTY) for deaf and disabled people. I can call people who don't have mail without the help of anyone. Here's how it works: I use my modem to dial the relay service. When I've made a connection, I type the number I want them to call. They read what I write on the computer to the person I'm calling. The agent writes back to me what the person says and I read it on my computer monitor. It is neat having "private" conversations. For the first time in my life I've had secrets.

develop and maintain friendships via electronic mail. Undoubtedly, telecommunications holds a great deal of promise for us all.

And the minuses

The drawbacks that exist for people with disabilities are the same for those without. Buying a computer can be costly, for example, especially if assistive equipment is also required. And if a child does not know how to use a computer, it may take some time before he or she feels comfortable exploring the "virtual universe."

There are many resources to explore in developing strategies for computer use at home, at school and on the job. COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES (see Media, page 50), by the Alliance for Technology Access, contains references for online services, books and periodicals that can be of use in this process.

The tools of technology are fabulously flexible. The possibilities are limited only by our imaginations. The challenge is to creatively maximize those tools' potential as our needs change and as technology transforms the ways in which we connect with our environment and the people in it. **EP**

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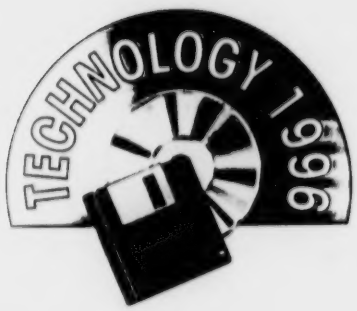

Got What it Takes to Get Online?

Have a pencil and pad ready!

by Bridgett Perry,
Perry & Associates, Technology Consultant for the Alliance for Technology Access

We've all heard reasons why people get on the Internet. We know there are lots of places to go and things to do! It leaves you wondering, "Can my family do that?" The answer lies in knowing what equipment you have and what you need.

Before you go out and buy any new equipment, see if you can test out a system locally at a dealership, user group or Alliance for Technology Access center. It is important to take into account what you would like to be able to do and which of the services and features you want to be able to access, and then look for the best system that can meet your needs at the price you want to pay.

The good news is that families can get online using commercial services that have made connecting to the Internet user-friendly, leaving the more complex paths to the Internet for technically-minded folks. The truth is, both paths will reap the same basic benefits: e-mail, newsgroups, file searches and transfers, and the now almost infamous World Wide Web (WWW). So what do you need to get online from your home computer? Here is a checklist and some guidelines to help you assess your Internet readiness.

Personal Computer

The better the equipment, the faster you will be able to access the information coming to you from the Internet. If you have the urge to keep up with the memory-hungry appetite of online sounds, video, animation and graphics, you will need a computer with a good deal of RAM (Random Access Memory or processing memory) and a lot of hard disk storage space (see the checklist).

Many families, however, can "do the basics"—such as electronic mail (e-mail)—with their old work-horse family computer. You may be limited in terms of power, however. If your older computer has a limited amount of RAM and you are using a commercial service such as America Online, CompuServe, Prodigy Online, Microsoft Network, GEnieNet, ask for an older copy of their software. If it is no longer available, check with a friend or a local computer-user group. As is true with all software, the earlier versions have lower equipment requirements because they were written for older standards. Even if a newer version of the software is available on the market, you still should be able to use the older software to open an account and connect to their online services.

Here is a checklist of equipment characteristics necessary for connecting online. It includes both suggestions and things to consider in putting together a system that will allow you to access the Internet. The items included in the "Suggestions" column are not minimal available requirements, but include enough power to enable you to access all of the bells, whistles and graphics currently used on the Internet. The "Considerations" column explains other options you have and what the differences would be.

Modem

The modem is the piece of equipment that connects your computer to the Internet using your telephone line. Some modems come as part of your computer package. There are internal modems that live inside the computer and there are external modems that live outside of your computer case. Either one does the same task of transmitting information back and forth between the Internet computers and your home computer. What makes a difference is the speed of the modem. The speed of transmission is measured in bits per second (bps). The higher the speed—or bps—the faster the modem can transmit information. This will be important to

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Splendor on the Internet

by Jason Holland

My friends and I tried out "America Online." I must tell you this is a very interesting tool. This allows you to do incredible things. You are able to "chat" with other users, send e-mail and join special groups having similar likes and tastes. I hope you could join in the splendor. Honestly, this is an incredible tool!

COMPUTER EQUIPMENT CHECKLIST

SUGGESTIONS	CONSIDERATIONS
TYPE OF PC:	
Processing chip 486 or better	386 will work with limitations
RAM:	
16 MB	-Less RAM will get you on a commercial service -8 MB is minimum for using the WWW -16 MB allows you to take advantage of all the graphics and sound
Hard Disk Space:	
5 MB	Earlier software used by commercial services is likely to require less space
Monitor:	
VGA or better	
Operating system:	
Windows 3.1 or better	MS DOS 3.3 will work with limitations
TYPE OF MACINTOSH:	
Processing chip 68040 or better	68020 or 68030 will work with limitations
RAM:	
16 MB	-Less RAM will get you on a commercial service -8 MB is minimum for using the WWW -16 MB allows you to take advantage of all the graphics and sound
Hard Disk Space:	
5 MB	Earlier software used by commercial services is likely to require less space
Monitor:	
256k or better	
Operating system:	
MacOS 7.1 or better	System requirements vary with the type of software you're using and its requirements

your family because it directly relates to the amount of time needed to access and pull up information on your computer screen. If you have a slower modem, access may take what can seem like an unbearable amount of time.

Another factor is cost. If you are using a service that charges you for the amount of time you are connected, a slower modem is going to use more time and therefore run up more service fees.

Telephone Service

The computer equipment and software make up one essential component of your system. The telephone line and service is the other key component you need to connect to the Internet.

Instead of dialing the phone number yourself, the computer dials for you. This does mean that when you are using the computer to send e-mail or explore the Web, your phone line will be busy! Some families have two phone lines in their home; one for phone calls, the other for the computer. Obviously, you will have to pay the phone company for the use of the second line and this can be an unwanted or unnecessary added expense. Just as you would have family rules and agreements about using the phone at home, you may want to set rules for using the phone for playing online!

Most Internet services have local-access numbers for you to use when connecting to the Internet. If you live in a remote or rural area, you may be required to place a toll call in order to connect to your Internet service. These charges can add up quickly in addition to regular service fees. Fortunately, as the Internet becomes more widely used, local connections are more available to a broader range of communities across the country.

Internet connection

An Internet Service Provider (ISP) is a company that, for a fee, allows you to use their connection to the Internet. This means your computer dials a phone number that is answered by a "server," that is, another computer. The server allows you to reach the Internet and access thousands of other computers, each with its own information treasure trove. This makes some people nervous. Be assured: though outsiders can send messages to you over the Internet, the Internet's "thousands of other computers" cannot tap into the information you keep on your home computer. You

continued on page 40

Talkin' Tech

KIDS COMMUNICATE THROUGH ADAPTIVE TECHNOLOGY

Don't Give Up

by Chrissy Stitt

I like to talk. I no I kan tell many things people want to know about computers. But most important I think is to believe that you can do it! try all kinds of stuff. if you don't like it don't use it. If you do like it try very hard to learn how to use it. Don't give up. I didn't now I can talk with a computer and intellikeys!

998

continued from page 38

would have to set your computer up with complex configurations and connections to do that.

Selecting an Internet Service Provider (ISP) will depend on the fees, your geographical location, the amount of time you are online, the type of computer you are using and what you will want to do once you are online. Most services today allow you to exchange e-mail, transfer files, search databases, browse the World Wide Web and even use some of their server space to store your own web page for others to view. Using an ISP can be cost effective if you are on many hours a month. However, it can also require a bit more technical know-how and maintenance than a commercial service does.

Commercial services are an easier way to get into the Internet. These services are like belonging to an Internet community that allows you to exchange e-mail, access bulletin boards where you can read and post information, explore online reference materials such as encyclopedias and dictionaries, magazines and newspapers, visit chat rooms where you "talk" with others on specific topics of interest and access vast software libraries that you can download to your own computer.

Ask other families what Internet services worked best for them and why. The advantages and drawbacks they list might be the feedback you need to make the right decisions for your family. The issues may range from the ease of use, to the compatibility of an access device used by someone in your family—such as a screen reader with speech synthesizers which verbalize everything seen on the screen.

You have, no doubt, received software in the mail inviting you to preview an Internet service. This is a good way to check out what is available and see what works well for you. Though the first five to 10 hours of these preview offers may be "free," you will be asked for a credit card to activate an account, even temporarily. If you decide not to continue the account beyond the preview time, it is up to *you* to inform the service. If you do not cancel, a charge for the next monthly fees will be automatically billed to your credit card.

Software

Whether you choose an ISP or a commercial service to get online, you will need software to connect your computer with the service. Software that comes from a commercial service usually includes everything you will need, including the software to run the modem. This is a fairly user-friendly way to go and installing and using the program is generally easier. The commercial-service software relies heavily on the use of graphics—you make choices and selections by pointing to pictures (or icons) and clicking the mouse button.

It is important to note here that the use of these graphic-based systems can present problems if you need to use assistive technology to access your computer.

The best example of this is someone who can't see the computer screen well and uses a program called a "screen reader" to "verbalize" everything on the screen. Although these programs are getting better, they still have difficulty interpreting graphic images. On the other hand, screen readers that are designed to work with straight text do a very good job. Many of the ISP providers use text-based software, so you may want to look into going this route rather than using a commercial service, if this is an issue.

ISPs may provide connection software but often installing it can be somewhat complicated. There are a lot of folks out there who know how to do it and could help you figure it out; you just need to ask.

Talkin' Tech

KIDS COMMUNICATE THROUGH ADAPTIVE TECHNOLOGY

The Show

by Stacy Brock

THE STARS PEEK THROUGH
THE NOW BLUE CURTAIN WAITING,
WAITING FOR THE NIGHT.

SLOWLY, THEY COME OUT ONE
BY ONE INTO A PERFECT DESIGN.

THE MOON COMES OUT AND
TAKES ITS FIRST BOW AND ALL
NIGHT LONG THEY ENTERTAIN.

THE STARS PEEK OUT FROM
BEHIND THE CURTAIN AND
THEY TAKE ONE LAST BOW,
THEN THEY FADE AWAY, SLOWLY
BEHIND THE CURTAIN AT THE
FIRST LIGHT OF DAY.

My name is Stacy Brock and I love to write poems and stories. I have cerebral palsy, so I can not write with my hands. To get my poems on paper I use a computer with adaptive equipment. The equipment is on loan from a center called Technology Assistance for Special Consumers (TASC). Without their help I would not be able to write.

Modem

RECOMMENDATIONS

28,800 bps modem (fast)

CONSIDERATIONS

- 14,400 bps will work for the WWW
- 9600 bps will do for email but not the WWW
- 2400 bps will do for email but is very slow
- you may want to consider the patience required to wait for some thing to appear on screen

999

Talkin' Tech

KIDS COMMUNICATE THROUGH ADAPTIVE TECHNOLOGY

Summer '96 Days at Christian Camp

by Michael Seale

I mostly swam all day long.
I also played charades with my new found friends.
It was fun to be doing the Preamble in the talent show at Arrowhead Springs Resort and Hotel.

P.S. the food was excellent!

As you get further into it, you will learn that there are different software packages that allow you to take advantage of different features and resources on the Internet, such as sending and receiving e-mail or exploring the World Wide Web. Some packages allow you to do it all, and some don't. But if you keep in mind your *goals* for getting on the Internet, making choices about software will become easier.

Resourcefulness

Now that you have a checklist of equipment needed to get online, you will want to inventory what you already have at home.

You don't have to become a computer techie to set things up. Be resourceful! If you find the task daunting or you simply don't have the time, find someone to help you. There are computer-user groups in many areas that have people ready, willing and able to guide you. You may have a teenager living next door who would love to set you up. There are also private consultants who can come to your home and get you started.

For more information on accessibility issues, you may want to call the Alliance for Technology Access center nearest you (see the list of ATA centers). They can help answer questions about access issues and the Internet. They can also point you to the increasing number of online services of specific interest to people with disabilities. More and more, organizations serving people with disabilities are maintaining World Wide Web sites and commercial services are offering specific resources geared toward this community.

The Internet is changing very rapidly. New resources and ways to use them are emerging daily. The Internet has already become a major educational, vocational and recreational tool used in schools, businesses and homes across the nation. An Internet connection is fast becoming a common household tool, just as the answering machine and VCR have. You just might be surprised to find that your family is only a modem or ISP away from getting online. Welcome to the Internet! **EP**

We gratefully acknowledge the assistance of InfoUse of Berkeley, California, in developing this article.

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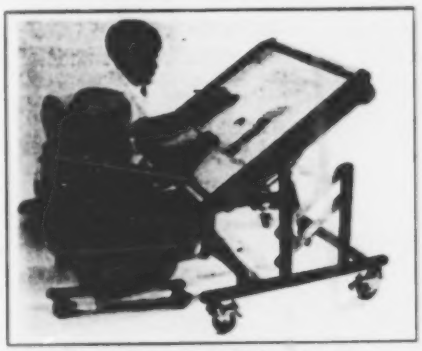

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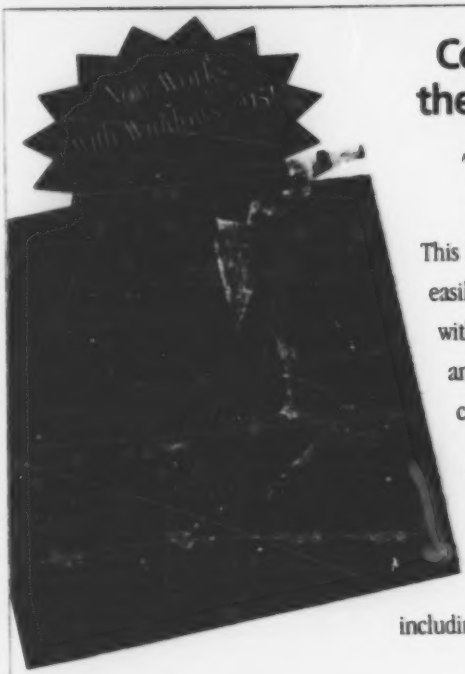

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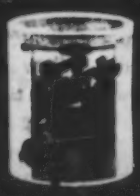

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A PARENTS' GUIDE TO ENTERAL NUTRITION
PART FOUR: Therapeutic positioning for eating and digestion

by Lee Barks

Positioning is a critical element in the success of both enteral and oral eating. However, often not enough attention is given to it as an essential ingredient in achieving the goal of good nutrition.

To achieve that goal, more needs to be going on than the intake of food. That intake must be accompanied by internal processes that result in successful digestion and, at the same time, maintain the basic function of breathing. While it may seem obvious, too often it is this goal that gets lost in the enthusiasm for helping the child to sit upright to eat.

Good positioning is essential in order to swallow or receive food through a tube and digest it properly, while continuing to breathe easily and comfortably. It is often overlooked as a relatively simple approach to what may otherwise become a medical treatment issue. If a child is not positioned well for receiving food, he or she may choke, vomit or have great difficulty breathing. The solution may not need to be as radical as going from oral to enteral feeding; but, rather, finding out why the choking, vomiting or breathing difficulty is occurring. The position in which the child gets nourishment may be causing the problem.

Knowledge here is the key. By understanding the internal processes that are going on when a child is trying to eat, parents can make important observations about why problems are occurring and work effectively with the child's physician, nurse and physical therapist (PT) or occupational therapist (OT) in helping to solve eating, digestion and nutrition issues.

The "inside" story

Eating and digestion require space. By this, I don't mean elbow room, but room inside. If a child cannot hold both body and head upright, it is hard for the internal events involved in swallowing and digesting to take place. That is why positioning as far as nutrition is concerned is so important. Health is as great a concern as comfort.

Positioning provides the body with an internal framework so that the digestion process can go on effectively inside it. If the body is slumping forward, the weight of the chest, head and shoulders is resting on the stomach. The result is too much pressure on the stomach. When it tries to pump food out into the small intestine, the result can be vomiting. If the head is extended forward, that can open the airway to food and fluids, and choking occurs.

The test for whether the child requires assistance with positioning is whether he or she can hold both the upper body and head upright enough to be in alignment with symmetry. (I will discuss this position more fully further on in this article.) If the answer to the "uprightness" question is "no" *for either* head or upper body, positioning should be considered. That consideration is really a two-part matter: seated positioning and sidelying positioning. In either case, gravity is a major part of the process. Seated positioning provides the direct path for food to follow in the most efficient manner. In sidelying, the point is to create "uprightness" and use gravity by providing an "incline." This is achieved through a piece of equipment referred to as a sidelyer (see the final picture in this article).

Postural stability

For a seated position to work, the child needs a stable base of support at the spine. The pelvis must be level—with equal weight on both hips—and slightly tilted forward. If this base of support is not established, the child will spend energy that is needed to maintain other functions—such as breathing and swallowing—just struggling to stay stable in a chair. Sometimes it is hard to remember that functions we think of as automatic or reflexive —swallowing and breathing—are jeopardized when instability demands constant attention and concentration.

To check a seated position, the child should be in an appropriately child-sized seat. The seat may be part of mobility equipment—a stroller, wheelchair or scooter. Check to see that the child's pelvis is in a slight forward tilt. This means the body, as seen from the side, is shaped like the letter "L." The lower back is curved *slightly* inward and the head is aligned over the shoulders. Be careful to avoid a "C"-shaped body position, with the head forward and the body folding toward the center.

If the child does not have enough muscle control to hold an "L" position, a level pelvis will not be enough to maintain stability. Support for both the forearms on a firm surface—a table surface, lap tray or broad-enough arm rests—

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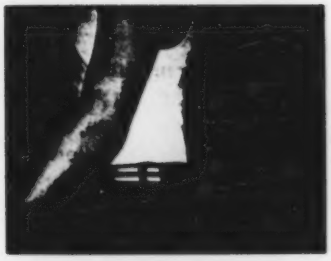
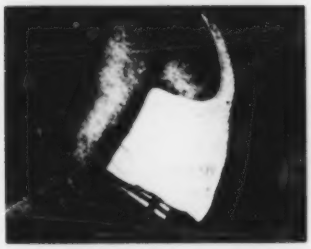


The "L" position provides the postural stability and support necessary for comfort, breathing and eating.

can take pressure off the stomach because it holds the shoulders up and bears the weight of the upper body. Added stability will come from having the child's feet firmly positioned on a footrest, the floor or a low stool.



Avoid the "C" position with the body toward into the center.

SEATED POSITIONING CHECKLIST:

- ❑ The child is in his or her own appropriately child-sized seat.
- ❑ The child's hips are positioned firmly and level at the back in the seat.
- ❑ The seat belt is firmly fastened under the child's pelvic bone.
- ❑ The child's forearms are firmly supported on a table surface, lap tray, or arm rest.
- ❑ Your child's feet are firmly positioned on a footrest, the floor, or a low stool.
- ❑ The child's chin is tucked slightly under.
- ❑ In the sitting position, the child's body is aligned and symmetrical.
- ❑ The child's breathing is easy and even, rather than labored, indicating no internal respiratory distress.

Alignment and symmetry

Along with establishing postural stability, a second critical aspect of therapeutic positioning is alignment and symmetry on both sides of the "midline." This means that if an imaginary line is drawn down the middle of the child's body, the left and right sides would look about the same, with parts of the body arranged fairly symmetrically on each side. The nose, navel, knees and toes should all point in the same direction. The head, neck and shoulders should be aligned and the legs parallel. If the child is eating orally, his or her neck should not be extended. The chin should be tucked forward a little to keep from opening the airway during a swallow.

If the neck is extended due to lack of alignment and symmetry on both sides of the "midline," the child's airway will open, allowing food or fluids to enter, resulting in choking (aspiration).

If these conditions cannot be sustained in the sitting position, sidelying is the mealtime alternative, even for children who *can* attain postural stability briefly. The average time for food to move out of the stomach—digestion—is two to two-and-a half hours. It may not be feasible or desirable to keep the child in a sidelyer for this extent of time. The clinical team can work together with parents to customize a positioning plan best-suited for the child.

Return to the goal: good nutrition. The issue is not only one of sitting, but of being in the best position to support digestion. Even for children who can sit, mealtime sitting may not equal that "best position" if alignment and symmetry cannot be maintained during digestion.

For example, scoliosis—or spinal curvature—can throw positioning off and influence digestion. This is because food must get down into the lower part of the stomach in order to stretch the stomach muscle and stimulate it to pump the food out to the small intestine. With scoliosis, it

continued on page 46

Scoliosis can complicate the flow of food in digestion.

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Circle #36

continued from page 45

may be difficult to achieve the alignment and symmetry to create the internal framework necessary for these internal functions. Sidelying would be appropriate at mealtime for children with scoliosis.

If seated positioning is not an option for mealtimes, inclined sidelying can really help the child. It can get him or her fairly aligned, keep the neck out of extension, and also take advantage of gravity which helps food go down to the stomach when swallowed. If the child is lying flat, food may pool or lie mostly on the posterior wall of the stomach and be vomited up hours later after it should have left the stomach.

Sidelying actually can have a plus over sitting. Inclined sidelying permits the tongue to come out easily and also allows for easier swallowing. A swallow occurs when the tip of the tongue rises up and rolls over the palate. Even if the child is being fed enterally, swallowing is usually still occurring. This is good. It not only helps the child swallow saliva, it primes the digestive tract all the way down.

Lying flat or inclined may cause food or formula to pooling the posterior wall of the stomach.

If the child is fed by tube, inclined right-sidelying helps food to flow from the stomach into the small intestine more easily. That is because food flows from top to bottom in the gastro-intestinal tract, and from left to right in the stomach.

Inclined sidelying can help the flow of food in digestion for children with scoliosis.

Make sure the child's trunk is elongated—stretched out and lengthened, rather than "crumpled." A shoulder that is held up and forward, for example, can inhibit breathing. These are basic approaches to sidelying. Different disabilities require different sidelying positioning. Therefore, for the safest use of such positions, check with your PT or OT to identify positions and the proper equipment to sustain them.

Equipment and support

Specialized equipment and supports help to maintain and

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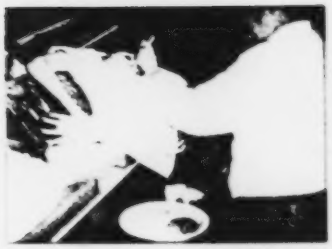

A sidelyer helps food take its natural route, flowing from top to bottom in the gastrointestinal tract,and from left to right in the stomach.

INCLINED SIDELYING CHECKLIST

- ❑ The child is aligned in the sidelyer, maintaining "midline" symmetry.
- ❑ The child's head is supported on a pillow or block.
- ❑ The child's shoulders, back, and hips are secure against the back of the sidelyer.
- ❑ The sidelyer straps are secure.
- ❑ The sidelyer provides support between underarms and hips.
- ❑ The child's bottom leg is straight in the sidelyer.
- ❑ The child's bottom arm is not caught under his or her body, but lies on the sidelyer surface, bent at the elbow and shoulder (see picture above).
- ❑ The child's breathing is easy and even, labored, indicating no internal respiratory distress.

support positions. If the child does not have trunk stability, without support, he or she will simply "crumple" in the middle, complicating the flow of food internally

In a seated position, if the seat is too long (too deep), it will be especially difficult to maintain a good position. A firm seat base and a firm, cushioned chair back are needed

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About This Series

This is the fourth in a five-part series on enteral nutrition and feeding. The earlier parts of the series include:

- Part One: When a Child Needs to Get Meals by Tube, August 1996
- Part Two: Care of the Stoma and Tube, September 1996
- Part Three: Nutritional Needs, October 1996

Part Five in the series will focus on weaning the child off of enteral feeding.

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Circle #37

Controlling Drooling

by David Hirsch, M.D.

Q Our daughter is almost 13-years-old and has cerebral palsy (spastic quadriplegia). She has always had a problem with drooling. Recently she has become more self-conscious about it and is afraid her classmates will make fun of her.

She seems to have no control over it, as much as she tries. She needs to wear a bib or "kerchief" around her neck to catch the drool. Often she drools on her books and other objects she is holding.

I have heard that there are operations that can be done to control drooling. We would prefer not to have any surgery done if possible, but our daughter is afraid that the other kids in junior high will make fun of her. What else can be done? Our daughter has handled her disability so well up to now. We would hate to see her embarrassed.

A Drooling, or sialorrhea (sigh-ah-loh-REE-ah), can be a major problem for people with various neurological conditions who have associated movement problems such as cerebral palsy, peripheral neuromuscular diseases and facial paralysis. Individuals with severe mental retardation—often as a result of neurological damage—may also have problems with drooling.

Most individuals swallow their saliva without even thinking about it. Excessive drooling is due to an inability of the brain to control and coordinate the muscles of the face and mouth, including the swallowing mechanism.

When drooling is severe (dripping from the lip to clothing) or profuse (dripping onto clothing and other objects), and it interferes with activities or creates social problems for the individual, treatment is indicated. Treatment would not be prescribed if the child was younger than four or if drooling occurred only during sleep.

The treatment of excessive drooling should always start with the least invasive method possible. Speech and occupational therapists use sensorimotor therapy combined with positioning and postural control to improve lip closure and swallowing. There are differences of opinion on the effectiveness of these approaches. Another less-invasive option, which is helpful for some individuals with mild-to-moderate drooling, is the use of an "appliance." This is a dental device that facilitates tighter lip closure when swallowing, directing the saliva to the back of the throat. The better the swallowing reflex, the better an appliance will work.

When less-invasive treatments have failed, there are two main options: medical and surgical. Medical treatment consists of using drugs to decrease the amount of saliva produced. The three most common medications that are used are scopolamine (scoh-POH-lah-meen), glycopyrrolate (glye-coh-PIE-roh-late) and atropine sulfate (EH-troh-peen suhl-fate).

Scopolamine is given as a "patch" which slowly releases medication through the skin. A 1994 study done at the Portsmouth Naval Hospital claimed that more than half of the children (ages five to 18) studied had "statistically significant" reduction of drooling while using the patch. I've had similar results using the patch, primarily with young adults. Unfortunately, the patch is not currently available due to problems with erratic absorption through the skin. It may be available next year. I do not know of any studies using scopolamine in other forms to control drooling.

I have more experience with glycopyrrolate or Robinul (ROH-bin-uhl) by trade name. A recent study of individuals at Gillette Children's Hospital in St. Paul, Minnesota (ages ranged from four to 27 years), showed that Robinul reduced drooling for nearly 70 percent of the participants. The perceived benefits were significant enough that 65 percent of the participants stayed on the medication when the study ended. In no case, however, was the drooling completely stopped. Though there were side effects requiring discontinuation of the medication for 11 percent of the users, this is a significantly lower percentage than has been seen with other medications that have been used to control excessive drooling.

Atrophine sulfate, marketed as Sal-Tropine, is a cheaper alternative to Robinul. Although I haven't used it in my practice, I am planning to try it with patients in the future.

The most common side effects of these medications are excessive dryness of the mouth, irritability, skin flushing, urinary retention, nose bleeds, constipation and headaches. Close follow-up by a physician is necessary, as it is any

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In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: Ask the Doctor, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).

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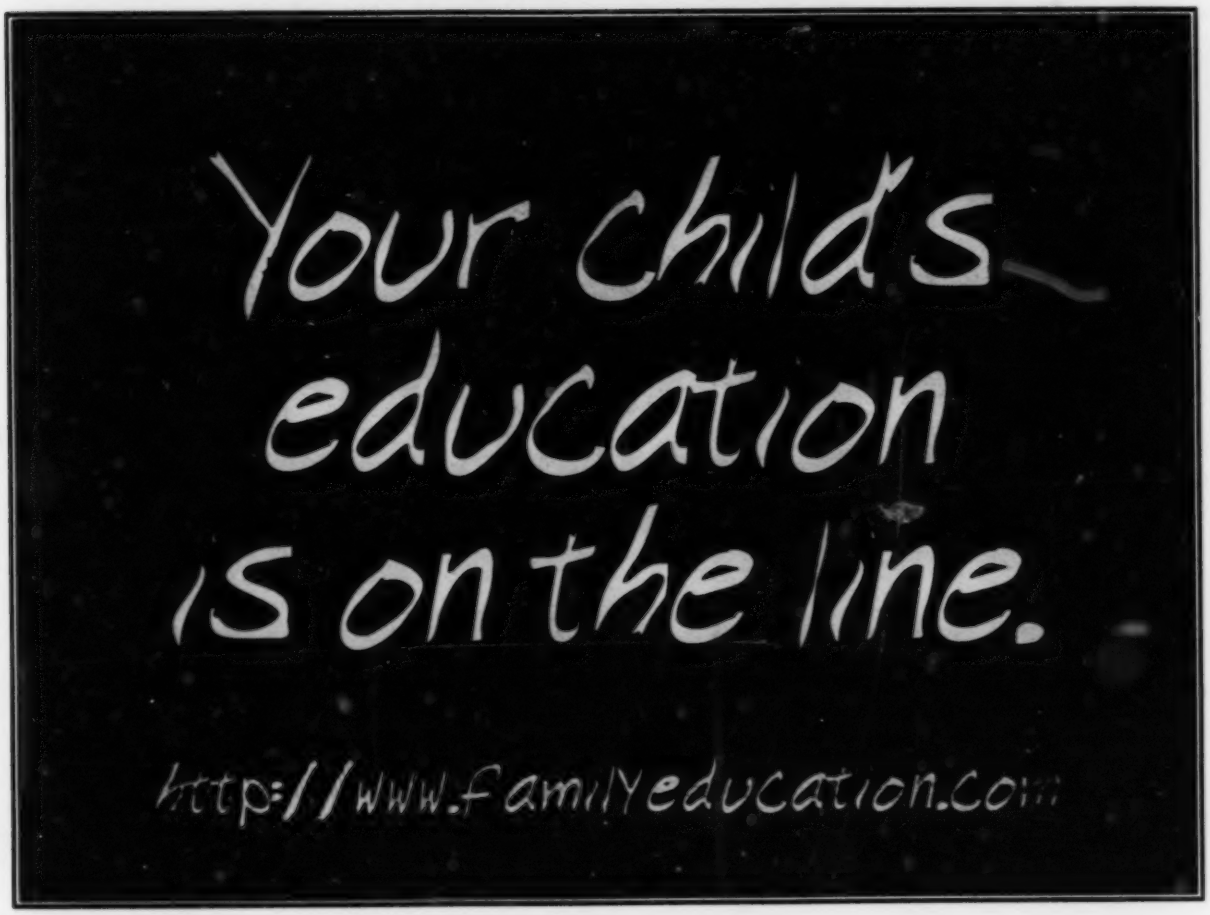

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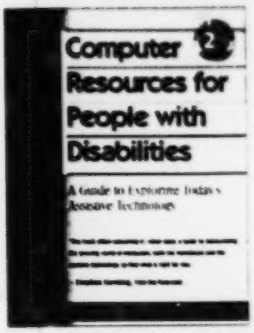
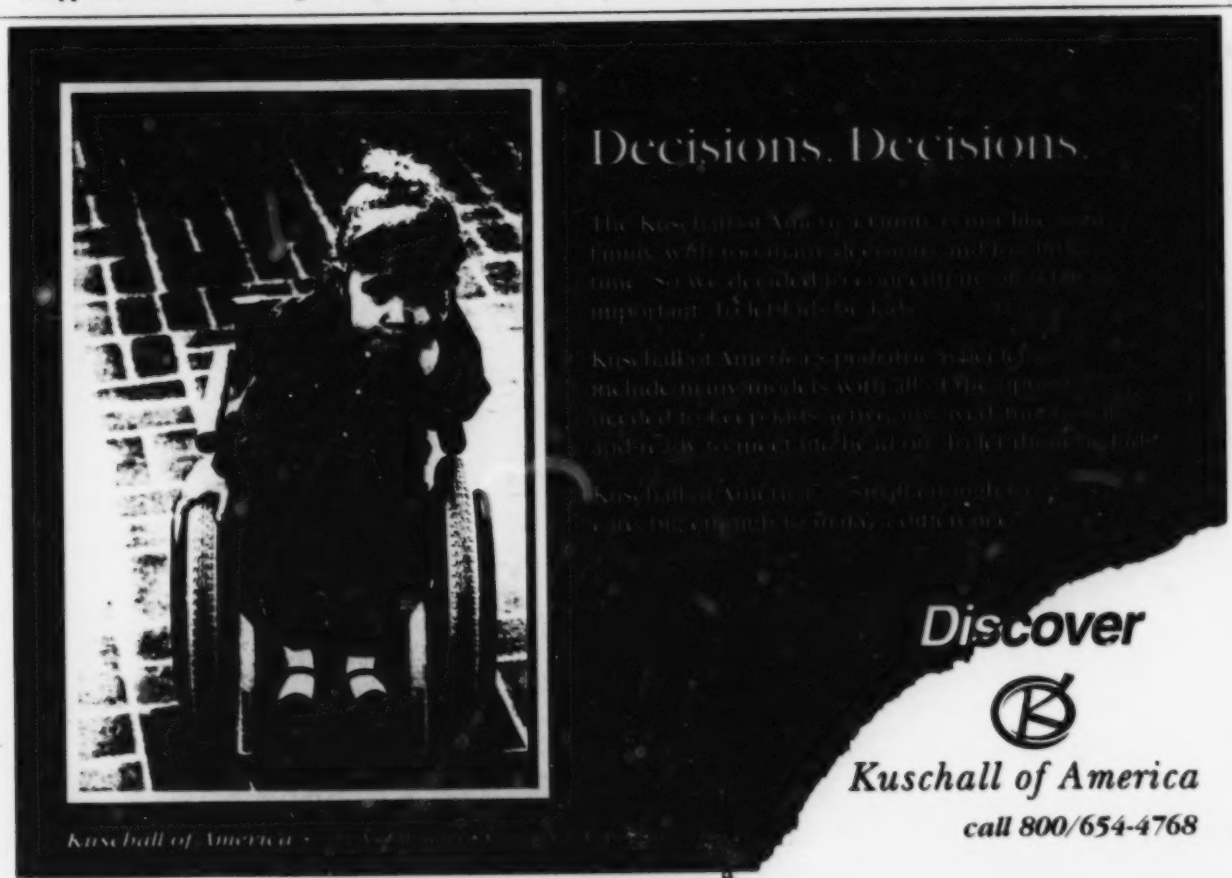


Produced "through a collaborative effort of the Alliance for Technology Access, its staff, board, volunteers, friends and families," COMPUTER RESOURCES FOR PEOPLE WITH DISABILITIES is an excellent guide to maneuvering the growing world of computers, both the mainstream and assistive technology. Written in clear, concise, "non-techie" language, its goal—which is sure to be admirably met, and admirably so—is to "help you begin answering questions for yourself, and to allow you to take advantage of the incredible new tools on the market today." The book is available from Exceptional Parent Library (800/535-1910). The following is an excerpt.

The Power of Expectations

From day one, you may hear about realistic expectations. It may come first from the medical community telling you that because of an identified medical condition, you must lower your expectations to avoid disappointment. At a kindergarten screening, you may be told that your child does not conform to the norms for her age and that you should reduce your expectations for her academic success or even her participation in mainstream education. At a parent-teacher conference, a teacher may suggest that you be more realistic, that you accept your child's placement in a classroom designed for children who are autistic, along with their notion of the appropriate expectations for autistic children. After a spinal cord or traumatic brain injury, you may be told that you will need to accept that there are things you will just not be able to do any longer. Or, as you grow older, you may be told that you can no longer participate socially or live independently at home.

We have all been told to be realistic in our expectations of ourselves (or others) based on someone else's best guess as to our ability and potential. Every expert has education and experience on which to base an opinion, yet none necessarily knows you or your child well. They may know about a physical or cognitive condition, but know little of who you really are: your personality, ambitions, goals, and drive. Experts are aware of some barriers to goal attainment and may recommend that you modify your goals. If you accept their recommendations for lowering your expectations,



Circle #68
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those diminished expectations may prove correct.

Most of us perform to the expectation level we and others set. If you are told that your reading level will never exceed fourth grade, and you are placed in a classroom where the expectations for students are just that, your reading level will likely be fourth grade. Your achievement often has more to do with the expectations and environment then with your real potential. We have seen far too many examples of the negative consequences of lowered expectations.

Jennifer came to our resource center in rural upstate New York in 1986 at the age of 18. She was minimally verbal and had been placed in a local developmental center at age two at the recommendation of the family physician. Jennifer's family was now exploring community living options because the developmental center was closing. Jennifer was learning the skills of daily living but had few opportunities for learning academic materials. She had written very little because of her poor fine-motor skills. In the course of her visit, she played with a talking word processor on a computer with a speech synthesizer. She was ecstatic at being able to make the computer speak and within a few minutes had demonstrated the ability to make it communicate whatever she wished. Eventually, Jennifer was moved to a foster home and attended special education classes, and in three years she was reading at an eighth-grade level.

Most of us aspire to similar goals: to reach our maximum potential, to participate in many aspects of community life, and to pursue gainful employment. Each of us puts different twists on these expectations and generally is free to do so. There are constraints—finances, academic achievement, prior experience—but our society affirms the right of most citizens to aspire to whatever they choose. It is that freedom that lets us think big and achieve big. It is also that freedom that enables us to decide to start all over again, to adopt new goals, to set new expectations, and to follow some paths many times over. The same freedom must apply to people with disabilities.

"Unrealistic" expectations may carry the dangers of disappointment, failure, or lack of fulfillment, but they enable us to apply all of our abilities in reaching our maximum potential. It is in our best interest to encourage them.

Conventional and assistive technologies empower children and adults who have disabilities with new abilities to communicate without speech or sight, to manipulate the environment with little or no physical dexterity, and to demonstrate cognitive abilities in nontraditional ways. The future holds even more promise and excitement for expanding the potential of all individuals. **EP**

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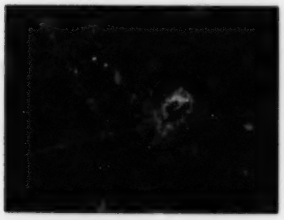

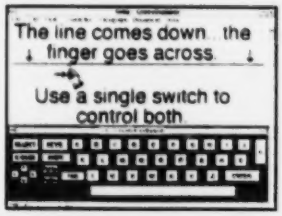

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Circle #58

Intrathecal Baclofen Therapy for Severe Spasticity

PART ONE

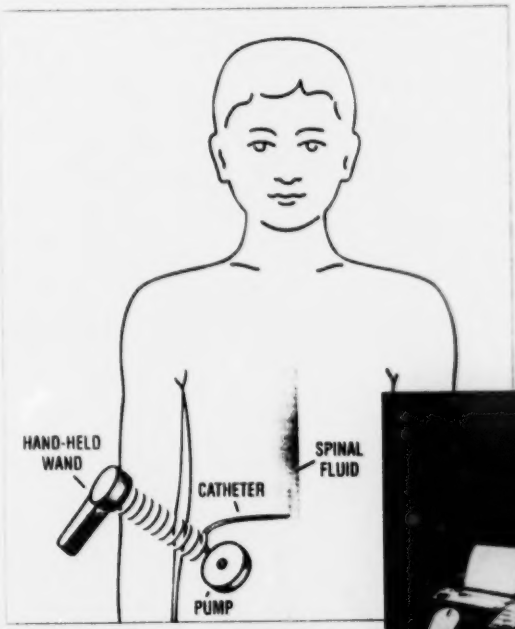
by A. Leland Albright, M.D.

EDITOR'S NOTE: In June, 1996, the U.S. Food and Drug Administration (FDA) approved Intrathecal Baclofen (ITB) Therapy, a new treatment for severe spasticity in children and adults with cerebral palsy and spinal cord injuries, as well as multiple sclerosis. ITB™ Therapy uses a drug, baclofen (trade name Lioresal Intrathecal), administered by a small pump that is surgically implanted, usually under the skin of the abdomen, as a treatment for spasticity (muscle stiffness common in many children and adults with cerebral palsy and some individuals with traumatic brain injuries). The device includes a reservoir (space for the liquid) inside a small pump. A tiny tube (catheter) delivers the drug into the spinal fluid. The pump is programmed via computer to release prescribed amounts of the drug to meet the needs of the individual.

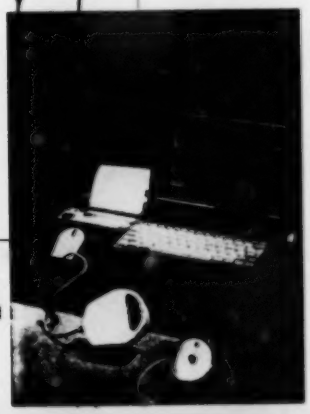
This article is the first in a series on ITB. It includes an article by A. Leland Albright, M.D., chief of the Department of Neurosurgery at the Children's Hospital in Pittsburgh, Pennsylvania, as well as brief reports from users of ITB. In the next series segment, the actual procedures used will be described in detail. In the third segment of this series, other treatments will be included in a discussion of the different intervention approaches for spasticity, so that consumers can be more informed about each available option.

Currently, while medical experts agree that each individual with cerebral palsy is different, there seems to be agreement among respected experts in spasticity management about the effectiveness of this treatment for patients who are appropriately selected. Though it is new for severe spasticity due to cerebral palsy and TBI (traumatic brain injury), ITB™ Therapy is not an experimental or controversial treatment for spasticity.

Spasticity is the term used for the involuntary muscle tightness and stiffness which occurs in about two-thirds of persons with cerebral palsy and approximately 100,000 persons each year with severe head injuries. Spasticity occurs because there is damage to areas of the brain which should send messages down to the spinal cord and tell it to release a relaxing chemical called GABA. Spasticity can affect any muscle—from those in the throat and neck, to those in the arms, trunk and legs—and may cause movements to be stiff, difficult and awkward.



Baclofen is delivered into spinal fluid by a pump implanted under the skin of the abdomen. A computer turns on the pump and programs it to deliver the baclofen.



It takes more energy to move spastic muscles than normal muscles. People with spastic cerebral palsy are often very tired by the afternoon because of the effort it takes to move about.

Spasticity and Contractions

Spasticity not only makes movements difficult or impossible, it may also cause muscle contractures. The experience can be similar to when a cast is used to help a bone fracture heal: The joint becomes stiff and muscle shortens. After the cast is removed, the muscle and joint are difficult to straighten out for several days. In the same vein, if a spastic biceps muscle constantly bends the elbow for several years, the bicep muscle becomes permanently shorter (contracted). Then, even if the spasticity is relieved, the elbow will not straighten out all the way without orthopedic surgery.

For years, physical therapists have treated spasticity with

exercises in order to attempt to keep joints movable and the range of motion of limbs as flexible as possible. Nonetheless, for many individuals, their spasticity has been more powerful than the therapy and caused multiple contractures. The contractures were then treated by multiple orthopedic operations.

Rhizotomy

In the mid-1980's, perhaps the first effective surgical treatment of spasticity became available: a neurosurgical operation, called selective dorsal (or posterior) rhizotomy (SDR). In SDR, neurosurgeons expose nerves in the spinal canal that are going to and from muscles in the legs and cut about 30-50 percent of the top (dorsal) half of each nerve. Afterward, spasticity in the legs is usually permanently relieved.

Improving Ali's World

by Debra Genova

Our daughter, Ali, was born thirteen weeks premature. She weighed two pounds, eight ounces. At about ten days old, Ali developed a grade four brain bleed, which scarred her brain and caused spastic cerebral palsy.

As Ali grew older, her spasticity grew worse. It was very difficult for her to do even the most simple movements. She was difficult to dress, bathe and feed. Her joints ached from being so tight all the time, and her startle reflex was almost to the point of being uncontrollable.

When Ali was six, we heard about a new drug therapy with a unique way of dispensing the medication. Baclofen is the drug, and an intrathecal pump is the delivery system. The baclofen "relaxes" Ali's stiffness, enabling her to move easier. Ali can now feed herself and help with bathing. She's much easier to dress, drives a power chair, and types. Overall, she's much more comfortable. Her startle reflex also decreased a great deal. Her whole world—and ours—has changed both in quality and ease of care because of this wonderful therapy.

Individuals who are appropriate rhizotomy candidates are usually young (four to seven years old is common), have relatively good leg strength, and do not have severe leg contractures. The operation, followed by intensive physical therapy, can improve walking—usually the primary goal. The operation can also be done to facilitate care at any age and usually loosens the tightened legs permanently, although it will not improve contractures that are already present.

Rhizotomies are not, however, appropriate for many individuals with cerebral palsy or brain injury who are

continued on page 54

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Joann Marner with son Christopher
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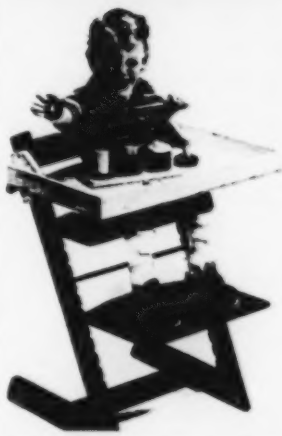
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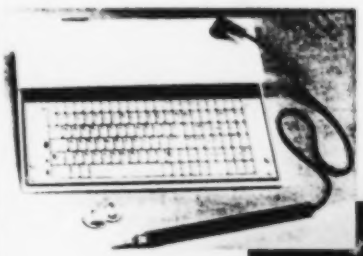

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A Great Answer

by T.J. Flack

Being born with a disability can be a difficult thing to deal with. Everyday tasks, such as getting dressed in the morning, taking a shower, or even brushing teeth can be both physically and emotionally draining.

These are just some of the things I've had to deal with growing up. Because of them, being born with spastic cerebral palsy did not lead to a "normal" childhood for me. However, since June of 1990, my life has taken a dramatic upward swing and I have the wonders of modern medicine to thank for it.

I should start at the beginning. In late 1989, I met with Dr. Leland Albright, head of Neurosurgery at Children's Hospital in Pittsburgh, Pennsylvania. I met with Dr. Albright to discuss the possibility of having a surgical procedure done that would reduce the spasticity in my legs. That procedure is called a rhizotomy, and it involves cutting nerve endings in the spinal cord to reduce spasticity. The drawback of this procedure is that the effects of this surgery, whether good or bad, are irreversible.

After discussing the possibility with Dr. Albright, it was decided that I would not be a good candidate for that procedure but for another one: Intrathecal Baclofen Therapy. Dr. Albright said the procedure was highly experimental, but in the few patients it had been tried on so far with cerebral palsy it was very effective.

After a brief trial period during which I was given Baclofen injections for a week, the procedure finally took place on June 20, 1990. The operation consisted of implanting a hockey-puck-shaped pump in my abdomen. The pump was then connected to a tube which is inserted at the base of the spine. The pump disperses baclofen through the tube to the base of the spine. The medicine is then dispersed through the catheter into the spinal fluid, which reduces the spasticity in my body.

The day the pump was inserted is one I will remember for the rest of my life. I can remember waking up from the surgery; immediately, I could feel its effects. Both my arms and legs felt like "spaghetti noodles," which was a little strange at first. But it was a good feeling. Then I can remember doing

continued from page 53

older, lack good leg strength, or are wary of an operation that cuts nerves permanently (the pros and cons of this procedure will be discussed in greater depth in the third segment of this series).

Intrathecal Baclofen

As noted above, spasticity is due to the inability of the brain to cause the release of the chemical GABA in the spinal cord. ITB therapy provides a substitute for GABA. Baclofen is a medication with a chemical makeup almost identical to GABA, and it functions in the same way.

If baclofen is given by mouth, it is not very effective because not much of it gets directly into the spinal cord unless very high doses are used; doses that often cause side effects such as drowsiness.

By putting baclofen directly into the spinal fluid which surrounds the spinal cord, it can spread into the cord and replace the body's normal GABA. Because baclofen is deliv-

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something I had never been able to do all my life up to that point. I raised my hands over my head completely for the first time.

That feeling was just the beginning. After surgery, I had to go to rehabilitation to train my legs to walk on their own and not on the spasticity they had been walking on for as long as I can remember. While I was there, I also discovered that I could do everyday things such as get dressed and take a shower much more easily. Instead of taking me 20 minutes to get ready in the morning, it now took me just five minutes. Also, it would only take me 15 minutes to take a shower instead of the 45 minutes it had taken before I had the pump.

All of these things helped me with something that I needed badly—confidence. For the first time in my life, I was able to do things on my own and without the help of my parents. Because of the pump, I now drive a car with hand controls, play wheelchair basketball and I am currently attending school to become a travel agent.

All of this would not have been possible were it not for the fact that my parents asked questions about the new procedure. I think that is the most important part of anything new. Ask questions about what you don't understand; you may be surprised at how well things could turn out. Look at how things turned out for me.

ered directly into the spinal fluid, only tiny amounts are needed: usually 150-350 micrograms (about 1/100th of a teaspoon) per day—some 200 times less than an oral dose.

Baclofen is delivered into the spinal fluid by a pump which is implanted under the skin of the abdomen in an operation that lasts about two hours. A small tube is connected to the pump and is tunneled under the skin around to the back. There, an even smaller tube is inserted through a needle into the spinal fluid. The two tubes are connected together under the skin. The pump is then turned on by a computer and is programmed to deliver the baclofen. Doses of baclofen can be adjusted upward or downward, depending on the individual's response.

Pumps are refilled in the doctor's office about once every three months. Refills are done by injecting baclofen through a small needle inserted through the skin into the center of the pump. The pump battery lasts about four to five years. The entire pump is then replaced.

continued on page 56

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Circle #34

continued from page 55

Because baclofen in the spinal fluid flows upward all the way to the head, it may relax the entire body, including the neck, arms, trunk and legs. Some individuals have improved alertness, swallowing, communication, upper extremity (arms, hands) function—including gaining skills needed to use communication devices—trunk control or gait. Others have improved their ability to tolerate ankle-foot orthoses (type of braces), sit in their wheelchair or scooter more comfortably or have better endurance. Not all the improvements occur in each individual.

Team assessment

When approached by parents of a child with spasticity, we ask them to send us a videotape of their child walking or sitting, feeding themselves, rolling over or crawling—whatever the child can do—along with a medical summary and a report from the physical therapist.

Perhaps half of the inquiries we receive are in reference to children or adults with cerebral palsy who have movement disorders, but do not have spasticity. Rather, they have some other type of movement disorder. Many of these individuals can be helped, but not always by ITB.

If it looks like the spasticity is fairly severe and is impeding function and/or making it hard for to care for the individual, we explain that it would probably be worthwhile for the child or adult to have a comprehensive assessment in a multidisciplinary clinical setting. For example, in our clinic, six different specialists see each individual: a physical therapist, an occupational therapist, a social worker and three physicians with different areas of specialty—a neurosurgeon and a physiatrist (a physician who specializes in rehabilitation). Ideally, children or adults who are considering ITB are evaluated in a clinic by a similar team of specialists. Such a multidisciplinary team needs to have experience in all the current treatments for spasticity, including oral medications, rhizotomy, botulinum injections (into spastic muscles) and ITB.

At our clinic, each team member examines the child independently. Then we sit down together and have a conference. Each specialist discusses his or her observations and treatment recommendations. Sometimes it is very clear that an individual's goals are best served by one specific procedure or another. Sometimes, when it is not clear, we say we are not sure and ask to re-examine the child in six or twelve months. Currently at our clinic we have recommended ITB treatment for 25 to 30 percent of the new individuals who have been referred.

In next month's article segment, we will give a detailed look at what ITB treatment entails and what can be expected before, during and after the surgical procedure. **EP**

A. Leland Albright, M.D. is chief of the Department of Pediatric Neurosurgery at the Children's Hospital of Pittsburgh. He also serves as Professor of Neurosurgery at the University of Pittsburgh School of Medicine. He is the leading researcher in Intrathecal Baclofen Therapy (ITB) in the United States.

We appreciate Dr. Albright's readiness to work with us. Almost nine years ago, Dr. Albright learned of the use of ITB by a colleague in Chicago for adults with spinal cord injuries and multiple sclerosis. "From what I knew about the physiology of spasticity," he says, "it made sense to me that it ought to work in children with cerebral palsy as well. I applied to the FDA and got permission to start testing it." As a result, the first U.S. studies of ITB in individuals with cerebral palsy and brain injury were begun at Children's Hospital in Pittsburgh in 1989. Gradually, other specialists in the United States and Canada also received FDA permission to test ITB.

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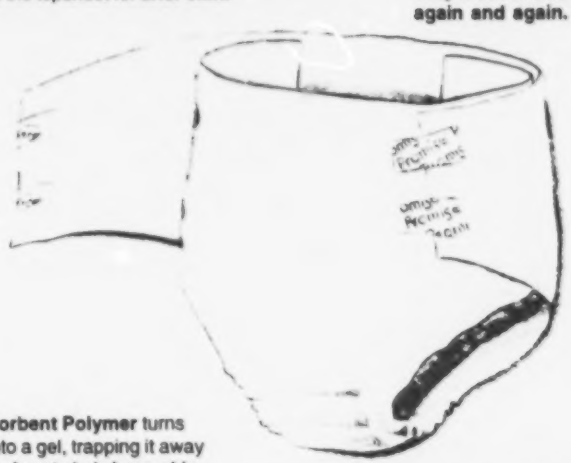

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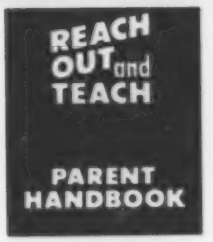

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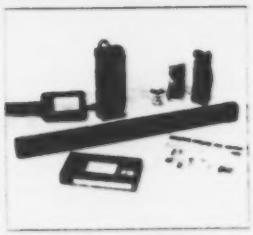

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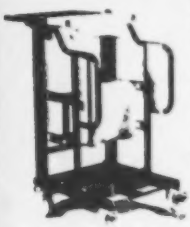

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A SOUND SOLUTION

PART ONE: Determining the best hearing device for your child.

by Debra D'Agostino

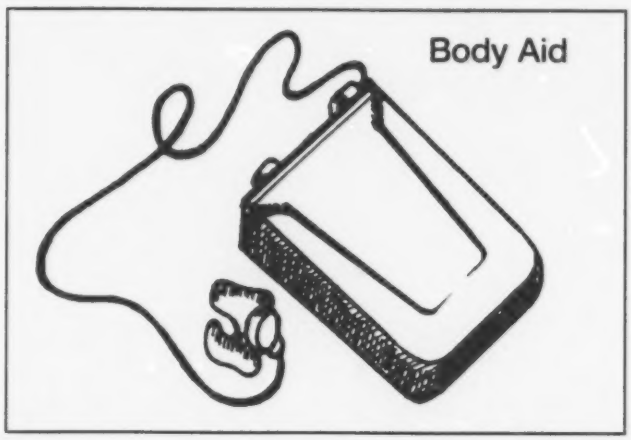
THE BIGGEST DIFFERENCES BETWEEN HEARING AIDS RELATE TO SIZE, LOCATION AND THE PRICE OF THE DEVICE.

When looking for the best hearing aid for your child, there are a number of things to consider. Specifically, Kathryn Laudin Beauchaine, M.A., an audiologist for Boys Town National Research Hospital in Omaha, Nebraska, says there are three characteristics that are important to consider when choosing hearing aids for children. First is *frequency response*, which determines the range of sound for which a hearing aid must compensate. The second is *gain*, the amount of actual amplification the hearing aid *can* provide. Third is the *saturation sound pressure level* (SSPL), the loudest sound the aid can create. The SSPL must be adjusted so it will not be too loud for the child, causing not only discomfort, but additional damage as well.

Device differences

"The main thing when looking for a hearing aid is to find the best fit for the patient," says Larry Higdon, Vice President of the American Speech-Language-Hearing Association (ASHA). Generally, all hearing aids work the same way and have similar parts. A microphone picks up sound, and an amplifier makes it louder. A miniature loudspeaker delivers that louder sound into the ear.

The biggest differences between hearing aids relate to the size, location and the price of the device. Beauchaine says a hearing aid can cost anywhere from $600 up to $2,000.



The most common hearing aids are:

Behind-the-ear-aids. These devices fit in a small case that sits behind the ear. The case connects by clear tubing to an ear molding through which the sound is delivered into the ear.

This aid is suitable for all ages and for any degree of hearing loss.

Bodyaids. Designed to house the main elements of the hearing aid in a rectangular case, these devices fit in a shirt pocket, can be

continued on page 60

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Your baby looks normal... yet you know something is wrong.

Your child cries so softly and so rarely...seems to have little interest in eating or nursing...doesn't respond to people or objects...doesn't recover from colds... vomits frequently...is limp and always tired.

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What is it? Carnitine is a naturally occurring substance that helps turn the food we eat into energy and protects the body from accumulating toxins that interfere with energy production. Babies and young children lack the enzyme to make their own supply of carnitine, but in most cases obtain the necessary supply from dairy products, breast milk, infant formula and red meats in their diet. Infants and children may be carnitine deficient due to a failure to transport carnitine into the cells. This is called primary carnitine deficiency. A deficiency resulting from poor dietary intake or a metabolic disease which depletes the body's stores of carnitine is called secondary carnitine deficiency.

What are the symptoms? Very poor muscle tone and coordination, chronic vomiting and fever, severe feeding problems, failure to thrive, little weight gain and/or weight loss, lethargy and unusual weakness, recurrent infections, flu-like symptoms, seizures or loss of seizure control, liver dysfunction and poor cardiac function.

What can you do? Consider the possibility that your child has a metabolic disorder if traditional treatments for a health problem don't seem to be working. Ask your pediatrician to check your child's carnitine plasma level. Be aware that carnitine deficiency is a symptom of metabolic disorders and further examination by a metabolic disease specialist is needed. Treatment for carnitine deficiency is simple and fast acting in acute cases. Contact Assistance for Babies and Children with Carnitine Deficiency for more information and support.

A parent-founded organization which serves as a source of support and guidance for the families of carnitine deficient children.

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Circle #64

1018

BODY AIDS CAN BE USED BY CHILDREN WHO HAVE REDUCED DEXTERITY BECAUSE THE CONTROLS ARE LOCATED ON THE CASING.

Canal Aid

continued from page 58

worn like a necklace, or otherwise attached to the clothing. A cord connecting the receiver snaps into the earmold.

Body aids can be used by children who have reduced dexterity because the controls are located on the casing, not in the earmold. In addition, controls can be made larger to accommodate children with additional disabilities.

Canal aids. Canal aids are contained in a small case that fits either partly or entirely into the ear canal. These are the smallest aids available on the market, which makes them cosmetically appealing.

However, these aids are not usually recommended for children. The hard plastic casing can be irritating. Also, for a canal aid to be effective, it should fit snugly within the ear, creating a seal that blocks out background noise. Because a child's ear is constantly growing, canal aids require constant refitting.

All-in-the-ear aids. Larger than canal aids, these devices extend out of the canal and sit in the ear. These, however, are also not usually recommended for children because of the hard casing and fitting requirements.

Another problem with aids that fit into

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Circle #59

1019

the ear is that they can be easily damaged by ear wax or ear drainage.

Cochlear implants. The small parts of this device are surgically inserted into the inner ear. The transmitter and microphone resemble a behind-the-ear aid that connects to a small speech processor that fits into a pocket. Beauchaine notes, however, that this type of device is only recommended for children with profound hearing loss, for whom other devices do not work.

Bone conduction. These types of hearing devices are good for children whose ears are irregular and undeveloped and cannot support a traditional device. The bone conduction aid is worn on a headband that fits snugly next to the head. Using the child's bone structure as a conductor, vibrations transmit sound.

Other alternatives

What if your child already has a hearing aid but still has trouble hearing others because he or she uses a respirator, ventilator or other device that makes constant sound? Beauchaine recommends using an FM (frequency modulated) system.

FM systems are basically additional amplifiers that block out background noise. A teacher, parent or other caregiver wears a microphone from which sound is picked up by a system in the child's hearing aid.

"The whole point of this system," Beauchaine says, "is to take away the background noise and make up for distance." Regardless of the parent's proximity to the child the sound is transmitted at a constant level.

Michael P. Sabo, an audiologist at Good Samaritan Regional Medical Center in Phoenix, Arizona, says he is a strong believer in FM systems because it gives parents greater control in cases where a child with severe disabilities is unable to give appropriate feedback about how well a hearing aid is working. "Parents can monitor what information the child is getting and make sure he or she is getting it continually," he says.

However, "You have to look at each case individually," Sabo says. "Parents need to develop the best intervention strategy based on the child's needs." **EP**

A comprehensive listing of organizations for individuals with hearing impairments can be found in EXCEPTIONAL PARENT's Annual Resource Guide (the January issue). Thanks to ASHA for providing the sketches used in this article.

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- Sternberg, Les, Ronald L. Taylor & Steven C. Russell—**NEGOTIATING THE DISABILITY MAZE: Critical Knowledge for Parents, Professionals, and Other Caring Persons. (2nd Ed.).** '96, 184 pp. (7 x 10).
- Durán, Elva—**TEACHING STUDENTS WITH MODERATE/SEVERE DISABILITIES, INCLUDING AUTISM: Strategies for Second Language Learners in Inclusive Settings. (2nd Ed.)** '96, 390 pp. (7 x 10), 28 tables.
- Jones, Carroll J.—**AN INTRODUCTION TO THE NATURE AND NEEDS OF STUDENTS WITH MILD DISABILITIES.** '96, 268 pp. (7 x 10), 4 tables.
- Bishop, Virginia E.—**TEACHING VISUALLY IMPAIRED CHILDREN. (2nd Ed.)** '96, 274 pp. (7 x 10), 15 il., 6 tables, $48.95, cloth, $33.95, paper.
- Anderson, Frances E.—**ART-CENTERED EDUCATION AND THERAPY FOR CHILDREN WITH DISABILITIES.** '94, 284 pp. (6 3/4 x 9 3/4), 100 il., 14 tables, $44.95, cloth, $29.95, paper.
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Children's Health Notes

High Tech—High Touch

By Chad Pierro

When children with disabilities grow up using technology, they expand their worlds and increase independence.

Access to computers expands the world for a youth with disabilities.

It is never too late for parents to encourage their children with disabilities to dive in and learn what technology can offer them now and in the future.

For me, technology and communication went hand-in-hand in developing my own current work skills. I had access to computers and software in a computer programming class at school and at home. My parents consistently encouraged me to learn what I could at my own pace. My friends and I found activities we could be involved in together.

All these relationships helped me understand what I can do on my own as well as the areas in which I need assistance. Having the chance to express my fears and concerns along the way allowed me to feel comfortable with who I was and what I was doing. Today, as a professional, my past experiences are invaluable.

What Makes Technology Tick?

An assistive technology assessment can help answer that question.

Technology assessments may follow several paths, but should be based on a child's goals and dreams. A child with a speech disorder may find her voice through a voice synthesizer; a child with a physical disability may find new abilities through a leg brace designed specifically for his walking longer distances without pain; a deaf child might find delight in using computer programs with visual cues and sign language. Technology can provide a wealth of possibilities for a child's individual growth.

During an assessment conducted at school or through a rehabilitation program, families will be introduced to many professionals who may include occupational therapists, rehabilitation counselors, special education teachers, public health employees, and speech therapists. The assessment process may require some experimentation, but with family involvement, the child's needs will most often be successfully identified.

A list of questions can help guide the assessment:

- Are all skills being considered?
- Are your present and future needs and preferences being completely considered?
- Will the technology fit well into your home setting?

High Tech
Turn to page 64

Chad Pierro earned his B.A. degree in journalism at Augsburg College and is a free lance writer in the Twin Cities.

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- Is there more than one kind of technology that will meet your needs?
- Can the technology be used with other devices?
- Is the technology available for a trial period or test run?
- How easy is it to maintain the device?
- Is on-site service available?

Cashing In On Computers

On-line services such as America Online, Compuserve, and others provide a window to the outside world. A child can send electronic mail, explore the World Wide Web through established "home pages," or download new software to use on a personal computer. Accessing all these options may take some education for parents and children, but the Internet is becoming as common as televisions or telephones in homes, schools and libraries, and nearly as easy to use. Coupled with necessary adaptations, kids with disabilities can unlock the possibilities and opportunities the Internet provides.

Introducing a child with a disability to technology will enable her to realize her potential as a student and a person. For many children with disabilities, technology levels the playing field, allowing youth to meet new challenges with confidence.

Technology contributes to the fundamental aspects of development—mastery, independence, self-esteem—that promote a child's personal growth. Technology promotes communication and improves interactions with peers and adults; increases the success a child experiences at school, during playtime with peers, and at home with family members.

You can give no better gift to your child than the possibility to understand and realize how much he or she is really capable of doing. It may seem like a daunting enterprise to take on, but over time, you will find that your child can, indeed, be all that is possible.

Resources

"DO-IT" (Disabilities, Opportunities, Internetworking and Technology) has the goal of increasing the representation of individuals with disabilities in science, engineering, and mathematics academic programs and careers. They make use of computers, adaptive technologies, and the Internet network to facilitate communication and information access for people with disabilities. DO-IT publications and videotapes illustrate various aspects of the program. For information, contact:

Dr. Sheryl Burgstahler, Director
DO-IT
University of Washington
JE25/Room 206
Seattle, WA 98195
(206) 685-DO-IT

"Living in the State of Stuck," by M.J. Scherer, provides a discussion of the ways assistive technology is changing the lives of people with disabilities. The author focuses on two groups of people—those with spinal cord injuries and those born with severe disabling conditions. For information, contact:

Brookline Books
P.O. Box 1047
Cambridge, MA 02238
1-800-666-2665

"The New Language of Toys: Teaching Communication Skills to Children with Special Needs" is a guide for parents and teachers identifying stimulating and fun activities that use everyday toys to help develop communication skills in children. Chapters include: use of computer technology and language learning, videotapes and television, and toy dialogues. For information, contact:

Woodbine House
6510 Bells Mill Road
Bethesda, MD 20817
(301) 897-3570
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The Center for Children with Chronic Illness and Disability is a research and training center dedicated to the study and promotion of the psychological and social well-being of children with chronic conditions and their families.

The National Center for Youth with Disabilities has the mission of improving the health and social functioning of youth with disabilities through technical assistance and consultation, disseminating information, and increasing services between the health care system and others. For more information call: 612-626-3042 or 612-626-2825, or e-mail: c3id@gold.tc.umn.edu ncyd@gold.tc.umn.edu

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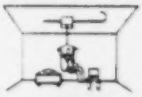

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Circle #46

Temperament: That Which Makes Us All Exceptional

by Peter A. Gorski, M.D., M.P.A.

Years ago, most "experts" believed that children grew into adults according to a genetically-programmed biological plan and that neither parents, teachers nor experiences along the way could alter the inevitable course of physical, mental, social or emotional development.

Then experts swung over to believing that the care-giving environment was the primary shaper of human development. Where, by whom and how a child was raised formed an individual's ultimate direction in adulthood.

In recent years, child-development experts have embraced a third perspective, one that recognizes the ever-present relationship between the child's inborn temperament and the characteristics of the child's care-giving environment. Temperament—one of the many components of personality—describes each child's unique, biologically-based, consistent pattern of behavioral responses to people, events and conditions.

Temperament is not determined by intelligence. Two people can be equally able intellectually, yet have remarkably different styles—temperaments—of expressing their abilities.

Everyone, including individuals with disabilities, at every age, shows a degree of response—high, medium, low—to nine behavioral categories influenced by temperament:

- Activity levels: Some people seem always to be in a state of flurry, others seem to exist on a level of permanent calm.
- Predominant mood: Some people

continued on page 68

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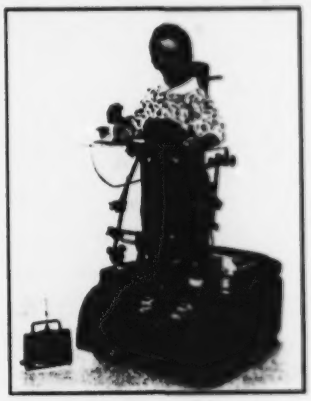

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Circle #19

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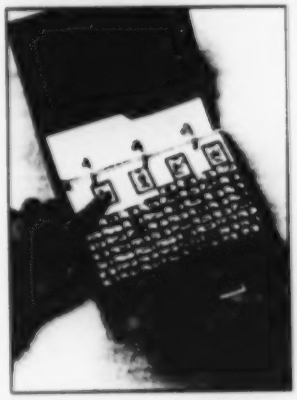

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BladderManager™
Personal Care Instrument

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DxU Diagnostic Ultrasound

Circle #69

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are born optimists, some pessimists.

• Intensity of reactions: Whether positive or negative, people express their feelings in degrees—more or less dramatically.

• Rhythmicity: Everyone has a degree regularity or predictability to body functions and personal habits.

• Approach/withdrawal: People's initial perception and response to change ranges from interest and openness to aversion.

• Adaptability: When confronted with new circumstances, some people can adjust right away, others take longer.

• Sensory threshold: Some people's senses seem that much sharper than others; some seem to get frustrated much easier than others.

• Attention span or persistence: One person will grab onto an idea or an effort with the intensity of a terrier; another gives up at the first obstacle or is always turning to new interests.

• Distractibility: Whether it is by sight, sound, odor, or any other sense, some people immediately turn their attention from what they are doing to pursue the distraction. Others continue on the path in which they were originally headed.

All children have the greatest opportunity to achieve personal happiness, self-esteem and productivity when they are fortunate to consistently live, learn and work with people who inspire and support their individual temperaments, as well as their unique abilities, interests and needs. We who love and advocate for children as family members and as professionals must be alert to the way children express how their current environment either facilitates or frustrates their interests and efforts.

For example, if a child clings to a parent when introduced to a new play group or program, is it because she or he doesn't have the necessary skills to join in, or is it because he or she hasn't had the time needed to adapt comfortably to the new circumstance?

Each child will experience development in uniquely individual and often predictable ways. If we are willing to look for, appreciate and support the nature as well as the abilities of each child at every stage, our children will fulfill their greatest potential and we will raise the net worth of our civilization. **EP**

Peter A. Gorski, M.D., M.P.A., is Director of the Blake Newborn Family unit at Massachusetts General Hospital, Assistant Professor of Pediatrics at Harvard Medical School, and Director of Professional Education at the Brazelton Institute of Boston Children's Hospital. His current research and advocacy work—which includes serving as President of the Society for Developmental and Behavioral Pediatrics—attempts to influence social and health policies toward comprehensive early-preventive support for optimal child development.

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Circle #35

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All Opinions But One

First-hand experience speaks

by Lisa Blumberg

In EXCEPTIONAL PARENT's continuing discussion of the tenor of March of Dimes advertising, all viewpoints have been represented but one—the viewpoint of those of us who were actually born with disabilities. Therefore, I hope you devote just a little more space to this topic.

For me, the issue is not whether a set of advertisements "inadvertently has offended some mothers who have done everything they could to have a healthy baby," but whether the advertisements that Teresa Wolding (March, 1996) and others have eloquently objected to make life harder for people with disabilities and parents of people with disabilities. I think that they do.

As Mary Jane Kitchens indicated in her perceptive article about her daughter, Mandy (September, 1996), people who are born with disabilities tend to feel just as much at home in their bodies as other people do. When others imply that a "birth defect" is necessarily a terrible thing, they are suggesting that there is something bad about us, that we are less than equal. This isolates us and increases the barriers to our full participation in society.

Parents of children with disabilities are better parents if they are allowed to accept their children with joy. How can they do that, though, if they see ads that they feel may cause other people to speculate whether their child's disability is somehow their fault?

I once heard an anthropologist who had studied the status of persons with disabilities in many different societies say that the way people born with disabilities are treated in any given society is a direct outgrowth of the way their parents are viewed. A society which respects and encourages parents of children with disabilities will invariably treat people with disabilities well. A society which views parents as being "the cause of the problem" will look at people with disabilities with disdain.

I feel that our own society is at a crossroads right now and that we all, including the March of Dimes, have a role to play in determining in which direction we will head.

I am glad to hear that the objectionable ads are no longer in use. However, I challenge the March of Dimes to expand its mission from reducing "birth defects" to one that is more positive—helping each child have the best possible start, regardless of his or her innate characteristics. This would include advocating for the maximum support to all pregnant women, new parents and infants, as well as promoting acceptance and appreciation of diversity in people. A good place for the March of Dimes to start would be to make sure that people with disabilities and parents of people with disabilities are amply represented on its board and in policy-making positions on its staff. **EP**

Lisa Blumberg is a member of the Editorial Advisory Board of EXCEPTIONAL PARENT magazine. Her first EXCEPTIONAL PARENT article was published in 1973 when she was a senior at Wellesley College in Massachusetts. Currently, she is a corporate attorney at Aetna in Hartford, Connecticut.

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Like a starving man at an all-you-can-eat buffet, I began to access information and resources. I attended workshops and conferences. I began to learn from other parents how to advocate efficiently. As before, I found myself the lone male in a room of a hundred women. I admired their tenacity and brilliance.

My wife and I applied the lessons I learned. Cayman entered his neighborhood school. This involved teaming with other parents and attending school board meetings and eventually filing a complaint with the Office of Civil Rights, U.S. Department of Education.

Once Cayman was provided appropriate services to enable him to learn alongside his non-disabled peers, we began noticing changes in him. While the stories he had written in the special school he had attended were only about his family, now he wrote about his friends. He began to blossom and was invited to birthday parties and sleepovers. He was appointed "Collier County Dreamer and Doer," a Walt Disney program honoring individuals who have become successful despite adversity.

Cayman Hawke was appointed "Collier County Dreamer and Doer" and awarded a medal by Miss America, who is also deaf.

He was even awarded a medal by Miss America, who is—like him—deaf.

Today, Cayman continues his success as an honor-roll student in regular education. His "commute" is just a five-minute bike ride down the street. As for me, I now work for the Family Network on Disabilities of Florida, teaching others the lessons I learned from my son.

The task of raising and advocating for a child with disabilities is enormous, too much for any one parent to go it alone. Mothers and fathers will find strength in working together for the well being of their entire family. I am happy to say that today I don't have to look very far in the crowd to find a Dad. **EP**

Wilbur Hawke is a 42-year-old father who lives on Macro Island in southwest Florida. He and his wife, Rhonda, have been married for 23 years. Wibur has worked for Family Network on Disabilities of Florida for four years, providing information and support to parents of children with special needs.

Because he believes informed parents make the best choices for their children, Wilbur hopes to help parents by maintaining the Family Network web site, which provides instant access to information for parents and professionals. The web site can be found at http://www.gate.net/~fnd/.

In his free time, Wilbur sits in the bleachers at basketball games and wrestling meets, pointing and saying "That one is my son."

Can We Talk?

Tell us about our WWW Special Needs channel!

The Family Education Network (FEN) Special Needs channel has, since September, given EXCEPTIONAL PARENT a lively and warm home on the World Wide Web. The online address for "Information that matters, from people who care" is **http://www.familyeducation.com.**

What do *you* think about the site? More important: How can we improve our home in Cyberspace to make you most comfortable and meet your special needs?

- *Is it easy to get from one place on the channel to another? What would make it easier?*
- *How easy is it to get in touch with other families and organizations online?.*
- *What feature do you use the most? Why?*
- *What feature do you like least? Again, why?*

Tell us about your Special Needs channel "wish list."

Quick: Fire us an e-mail at epfen@aol.com. Or, send us a letter at Special Needs Channel, Exceptional Parent, 555 Kinderkamack Rd., Oradell, New Jersey 07649.

We look forward to hearing from all of you!

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More Good News

With Usual Warnings

by Richard Epstein

Last month, I wrote about the changes in health-insurance law in the new "Portability and Accountability Act." I'm happy to report that three additional federal health-insurance laws that offer important new protections for many individuals and families have been passed by Congress and signed by the President.

Considering the intense philosophical and political conflicts generated by earlier health-insurance reform proposals, it's wonderful to see so many positive changes in health insurance law occurring now on the federal level. Unlike the "Portability and Accountability Act," however, these new laws—the "Mental Health Parity Act," the "Newborns' and Mothers' Health Protection Act," and the "Spina Bifida Act"—were included as part of a Veterans' Administration (VA) appropriations bill rather than passed as separate laws. Several of the laws may eventually be incorporated into the "Portability and Accountability Act" in the form of technical amendments.

As I noted in last month's column, new laws may be changed or reinterpreted as regulations are developed and implemented. Technical amendments also may be issued. In addition, there may be exceptions to some of the provisions in certain cases. Thus, it is important to remember that any discussion of these new laws is preliminary.

Mental Health Parity Act

An early proposed version of the "Portability and Accountability Act" included a provision that guaranteed "parity"—equality of benefits in terms of coverage—between the treatment of both mental and physical illness. Though the Mental Health Parity Act is not as inclusive as that earlier proposal, it does provide some relief in terms of benefit maximums. From now on, insurers and self-funded plans that offer coverage for mental-illness treatments cannot set yearly or life-time maximums at levels lower than the ones set for physical illness.

That is certainly good news, however note that the law refers only to yearly and life-time *maximums*. It does not require insurers to offer benefits for the treatment of mental illness, nor does it prohibit insurance policies from making other distinctions in areas such as deductibles and co-payments.

In addition, there are specific exclusions in and limits to the law that are important. First, the law applies only to group insurance plans sponsored by companies that have more than fifty employees. It does not apply to individual or small-group health-insurance policies. Second, if an insurer or company can demonstrate that the impact of the law increases the company's costs by one percent or more, they may be exempt from the law. Third, the law does not apply to the treatment of drug or alcohol problems.

Although the limitations may pose serious problems for some individuals, the "Mental Health Parity Act" is an important step forward. Aside from its direct benefits, the law also solidly establishes a new principle: The need for equality of benefits. Hopefully, laws that further refine that concept will follow in the future. The "Mental Health Parity Act" will go into effect in January of 1998.

Newborns' and Mothers' Health Protection Act

Many insurance companies have tried to limit hospital benefits following childbirth. Many consumers have felt strongly that such coverage should be provided for at least 48 hours. Several states have agreed, attempting to deal with the issue through legislation that would require insurers to provide such coverage.

However, a state's law affects only its particular state residents. Since self-funded plans—which are playing an increasingly important role in the American system of health insurance—are regulated by federal law, they would not generally be affected.

The "Newborns' and Mothers' Health Protection Act" solves that problem by requiring that all insurers and self-funded plans that offer coverage for childbirth generally provide a full 48 hours of coverage, increasing that to 96 hours in the case of a delivery by caesarean section. The law goes into effect in January of 1998. It is still important to know your state law, because it could take precedence if it provides similar or *additional* benefits.

Spina Bifida Act

The "Spina Bifida Act" provides a number of important benefits for eli-

continued on page 72

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

1030

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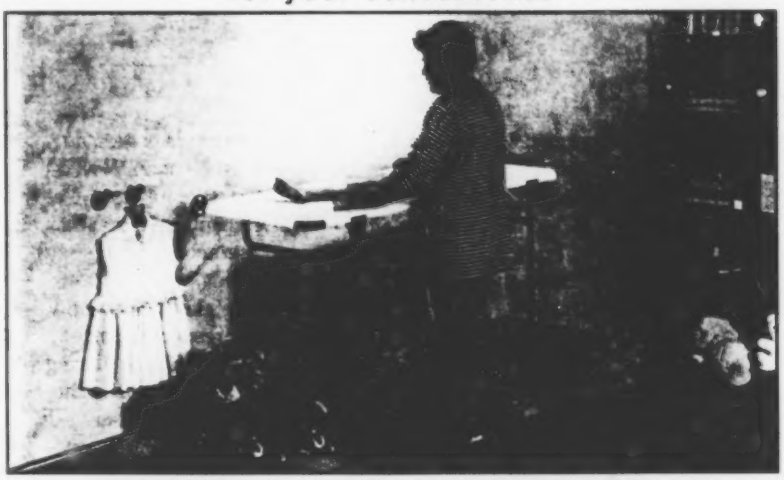

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Circle #48

HEALTH INSURANCE TROUBLESHOOTER

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gible children and adults with certain types of spina bifida whose biological parents were exposed to Agent Orange in Vietnam. Those benefits include health care—either through the VA or through a VA contract with another agency— as well as rehabilitation programs and other benefits.

Unfortunately, the program is not retroactive. Parents or individuals who meet the criteria of the law will not be reimbursed for funds that have already been spent for surgery or other types of medical expenses. At this point, the law is expected to go into effect in October of 1997.

The power of positive action

These new laws are enormously important for individuals and families. They, and the many other recent changes in health insurance laws on the state level, offer a clear demonstration that both the federal government and the various state governments listen closely to consumers. In the future, perhaps additional laws may be considered that would provide for insurance coverage for formula for children with disabilities who are unable to digest regular food, additional coverage for wheelchairs and other durable medical equipment, and increased benefits for the kinds of on-going services—physical therapy, speech therapy, occupational therapy—that many children with disabilities need so desperately.

The fact that these three new laws were passed illustrates the enormous potential power of average Americans who are united around a common goal. The government is unlikely to consider further legislation unless state and federal legislators hear from parents of children with disabilities and from organizations that represent their interests. **EP**

1031

WHAT'S HAPPENING

Pennies Campaign to Sail "Old Ironsides"

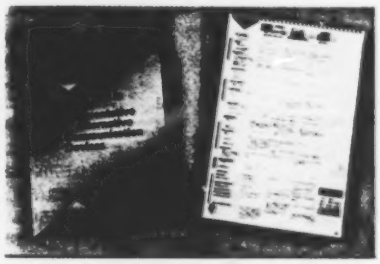
The USS Constitution, launched in 1797 and perhaps better known as Old Ironsides, is the oldest commissioned warship afloat in the world. On July 21, 1997, she will celebrate her bicentennial by conducting a special operational sail in Massachusetts Bay. It will be the first time since 1881 that the Constitution will sail under her own power.

But Old Ironsides needs your help! Children and parents are urged to contribute pennies to help raise money to pay for the sails needed to relaunch the ship. The "Sail Our Ship Pennies Campaign" is designed so the USS Constitution will sail because of individual—not corporate—donations. All money will go to the fitting out of the ship, not toward administrative or promotional expenses of any kind. The cost of making new sails and raising them is $500,000.

For more information, contact the USS Constitution Museum, PO Box 1812, Boston, MA 02129, or call (617) 426-1812. Donations can be sent directly to "Old Ironsides" Pennies Campaign, Charlestown Cooperative Bank, 201 Main Street, Charlestown, MA 02129.

Disability Solutions

Disability Solutions is a free bi-monthly publication providing practical, ready-to-use information to families of persons with Downs syndrome and related disabilities and the professionals who work with them. Readers are encouraged to submit articles, reviews, letters to the editor, or photographs. For more information, write Joan Medlen, Editor, at 9220 SW Barber Blvd., #119-179, Portland, OR 97219-5428.



Guide to AAC Devices

Keeping up with the changes in the field of Augmentative and Alternative Communications is a challenge. To help clinicians, consumers and funding agencies, the Rehabilitation Engineering Research Center on AAC at the Applied Science and Engineering Laboratories at the University of Delaware has produced the *GUIDE TO AUGMENTATIVE AND ALTERNATIVE COMMUNICATIONS DEVICES.*

The GUIDE includes descriptions of "traditional" AAC systems (from single-message voice output devices to computer-based systems supporting spoken and written communication), as well as descriptions for the "newcomer" categories of speech amplifiers and electronic artificial larynges.

Device descriptions are enhanced with a picture of each product.

Supplementary materials include: a Literature Notebook, a 3-ring binder containing manufacturer information on more than 50 products in the Guide; and a Slide Notebook, a 3-ring binder containing slides of all products profiled in the GUIDE, numbered and indexed for easy reference.

The cost for the GUIDE is $25.00. The literature notebook is also priced at $25.00, and the Slide notebook is $60.00. The total set is $100.00. All prices include shipping within the U.S.; add $2.00 per item for shipping to Canada. For more information, call (302) 651-6830.

Encouraging News About Employment

The U.S. Bureau of the Census recently conducted a survey with encouraging employment results. According to the Survey of Income Program and Participation, the employment population ratio for persons with disabilities increased from 23.3 percent in 1991 to 26.1 percent in 1994. During that time, approximately 800,000 more individuals with severe disabilities were working, which represents a 27 percent increase. For more information about the survey, contact Jack McNeil, Bureau of the Census, HHES Division, Room 307-1 Iverson Mall, Washington, DC 20233-8500, or call (301) 763-8300. **EP**

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ASK THE DOCTOR

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time medication is prescribed.

Surgical treatment consists of three main procedures. One or more can be done at the same time. The most straight-forward procedure involves one of the two major types of salivary glands: the submandibular (sub-man-DIB-yoo-ler) salivary glands. These glands, located in the lower jaw, produce most of the saliva. Transposition, or re-routing, of the ducts from these glands to the back of the mouth makes it easier to swallow the saliva. Re-routing of the ducts from the parotid (puh-RAH-tid) glands—the other major type of salivary glands, located in the cheeks near the upper molars—is technically more difficult, but sometimes done. Removal of the submandibular glands has also been done, but this is a much more difficult and prolonged procedure according to ear, nose and throat (ENT) surgeons with whom I have worked. It is important to consider that diverting the flow of saliva to the back of the throat can create problems such as aspiration (choking) if a child has an abnormal swallowing reflex. After carefully considering the possible complications and the likelihood of success in each individual case, an experienced ENT surgeon can often effect a significant improvement in drooling.

Keep in mind that no one treatment is always successful and a few have the potential for serious complications. You and your daughter should discuss any proposed treatment with her doctor. Be sure to ask lots of questions.

I am sure you are very proud of your daughter. It clearly is not her "fault" that she has excessive drooling or that conscious control is extremely difficult. While it can be very difficult for her not to be embarrassed sometimes by her disability, she should be proud of all she has accomplished. **EP**

A PARENT'S GUIDE TO ENTERAL NUTRITION: PART FOUR

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so the body can assume the "L" shape. A seat belt also helps to stabilize the pelvis and help the child maintain the "L." It should be attached snugly over the pelvis, not across the abdomen. The point of the seat belt is support, not restraint. It secures level positioning of the pelvis in the seat, providing the basis for postural stability. If the belt is positioned across the abdomen, it is not only uncomfortable. It may not be snug enough to secure the pelvis so that it is truly stable in the seat.

Support may also be needed on either side of the trunk and the head. Armrests or a lap tray can be provided to rest the forearms in a wheelchair. Additional support may be needed for the shoulders and on either side of the knees. Foot supports will keep the base of support evenly distributed across the child's thighs and feet.

Support is as important an issue for sidelying as for seated positioning. As mentioned above, the type of sidelying equipment used will depend on the child's specific needs. This is something to work out with your PT or OT.

A team effort

Mealtime is often not well understood in terms of attention to positioning and the difference positioning can make to nutrition. Mealtime is more of a parent-child occurrence. However, integrating the perspectives of therapists with this personal time can make a significant difference for the child's nutrition.

When therapeutic positioning for mealtime is necessary, the child has more ability to eat and digest food comfortably and safely. The object is to create an internal framework to allow critical internal functions—eating, digesting, breathing—to take place. Mealtime positioning is as important a discussion to have with the child's clinical team as how to help a child walk, roll over or dress. Understanding the processes that need to take place and the best approaches to supporting those processes can make parents effective partners on the child's clinical team.

Lee Barks, R.N., M.N., A.R.N.P., is the president and owner of Developmental Health, Inc., a firm that provides consulting services to rehabilitative and long-term-care programs. She also works as a pediatric nurse practitioner at Pediatrics Plus, a private practice in Orlando, Florida, and as a consultant to the early intervention program at the Arnold Palmer Hospital for Children and Women in Orlando. Lee lives near Orlando with her husband and teenage son and daughter.

Mary Bray, M.E.D., O.T. and Debra Gerber, P.T. were technical contributors to this article.

So, were you at Forum?

EXCEPTIONAL PARENT's first exhibition and conference, Forum '96, held on October 18-20 in Anaheim, California, was a fun time for exhibitors, parents and professionals alike. Attendees had the opportunity to meet one another, check out products and services for their children and families, and learn new advocacy skills.

EXCEPTIONAL PARENT thanks all who participated! We look forward to seeing you next year.

For those who missed Forum '96: Catch the highlights in the December issue of EXCEPTIONAL PARENT magazine. Meet the speakers, families, advocates and staff members that made Forum '96 a success. And find out why Forum '97 is an event you won't want to miss!

1034

NEW PRODUCTS

BLADDERMANAGER®

BladderManager is a portable ultrasound device designed to enable individuals with disabilities such as spinal cord injury or spina bifida to measure the amount of urine stored in their bladders, enabling them to know when urination or catheterization is required. The device enables users to catheterize or urinate based on bladder fullness rather than on a time schedule. To use the BladderManager, the individual positions the device's sensor near the pubic region and presses a button to activate the scanner. Once the information from the scan is processed, the results are displayed graphically and numerically on the control unit. The device can also be programmed to alert the user to perform a bladder scan at specified intervals.

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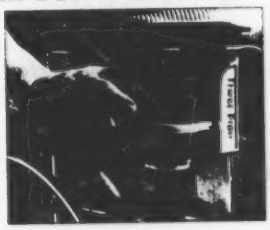

The Thirst Free Rail Cup Holder is a cup holder designed to enable wheelchair and walker users to keep a beverage easily within reach. Made of almond-colored polystyrene, the holder clamps to the side tubing on wheelchairs or the front bars on standard walkers, as well as to bed rails.

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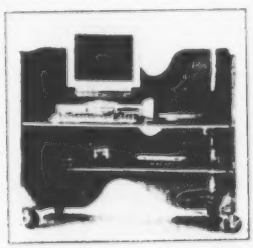

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The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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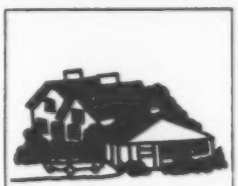

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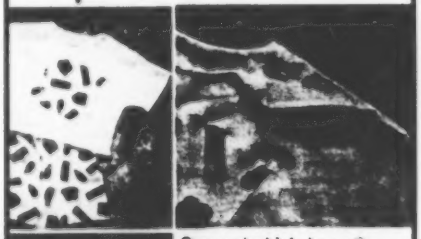

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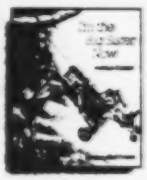

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CHILDREN'S PAGE

My name is Nathan Timerding. I am seven years old. I am in the second grade. I go to Chenoweth Elementary School in Louisville, Kentucky. I use a computer to talk to my friends and teachers, and to make choices. I am able to answer questions in class. Using my laptop, at school, I can tell my teacher where I would like to go and what I would like to do when I get there. I use a computer program called Speaking Dynamically. I like computers. I like music, going to the library and art. I like to play CD's on my computer. My favorites are Living Books. I use a special keyboard called Intellikeys to make the computer work. I can open up programs, close programs, move and click the mouse, type letters and numbers, and shut the computer down using my Intellikeys. Using a computer has helped me to talk better with people.

Thunderstorm

by E. Nathanael Timerding

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Drip
Splash

Wind Rain
Wet Rain
Drip

Rain

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Storm

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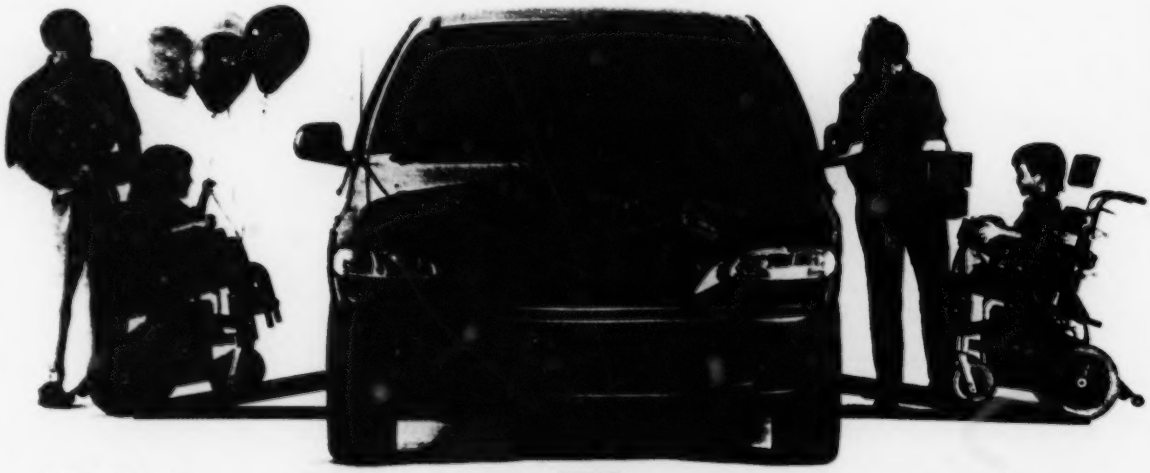
-Becky and Eric Timerding

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517.



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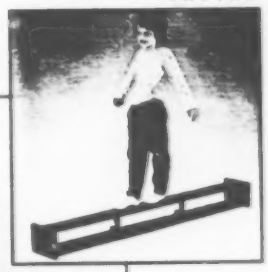

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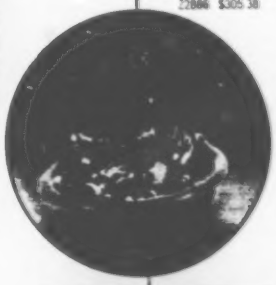

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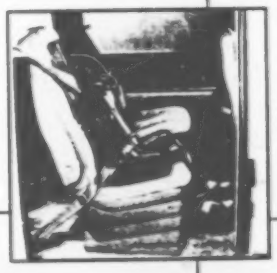

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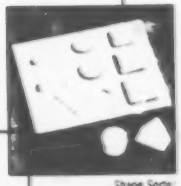

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Seascape Z5331-02 $38.21
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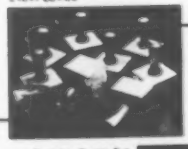
Porch Scene Z5331-04 $31.21



Assorted Sounds Set
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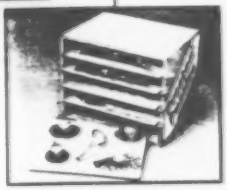

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EXCEPTIONAL PARENT

The Magazine for Families and Professionals

PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY

25th Anniversary 1971-1996

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Living In The Community

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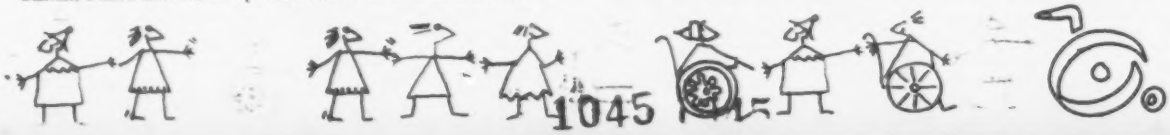

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EXCEPTIONAL PARENT
PARENTING YOUR CHILD OR YOUNG ADULT WITH A DISABILITY
25th Anniversary
The Magazine for Families and Professionals

DECEMBER 1996 VOL. 26, ISSUE 12

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Cover: Pam and Bill Ferro of Morgan Hill, California, pose with their daughter, Melissa, 8 1/2, and the Big Blue M&M at Exceptional Parent's first exhibition and conference! Thanks to M&M/Mars for all their help with Forum '96!

BPA

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EDITOR'S DESK

Becoming Part of a Community

STANLEY D. KLEIN, PH.D.

Adult living choices

"How will our child live as an adult? We may not be around and he may not be able to care of himself..." Parents everywhere ask me about the future. Years ago, there were few decent answers because so many people with disabilities live out their lives in institutional settings, many of which were disgraceful and degrading to the individuals with disabilities and their families.

Much has changed for the better. In this issue we report on different models for meeting individual needs of adult children with disabilities, developed by parents and professionals. We also include a major new national project through which policy makers are exploring new ways to enable individual adults with developmental disabilities and those close to them to plan and carry out programs to meet individual needs rather than depend on models of government-supported services designed for groups of people and managed at a distance. This effort is called "self-determination." Its goal is to support people where they choose to live and build a self-determined personal support system, rather than trying to bering individuals into human-service agency-supported housing or other programs.

In the future, I am hopeful that there will be more good choices for families. For example, my late parents spent their final years in a retirement community that included three different levels of support: independent living, supported living in one's own home and dependent care in a nursing-home setting. Now, I wonder whether some of the settings that serve individuals with significant disabilities could develop living settings for parents who want to remain near their family member while, at the same time, need some supports for themselves.

Health care, travel

In this issue, we complete the enteral feeding series and continue our series of articles on the treatment for spasticity.

We also initiate a quarterly feature on travel, an arrangement with ACCESS TO TRAVEL magazine. These articles spotlight travel and vacation adventures for families.

Our firsts and foremost

Forum '96 pictures are in! Our EXCEPTIONAL PARENT Scrapbook gives the feel of the fun and excitement of last October's event.

At Forum '96, I was delighted to meet karate pro Barry Atkinson, featured on our October 1995 cover. He gave me a few pointers, too.

As our exciting 25th anniversary year comes to a close, we want to express our appreciation to the various organizations who have honored us with awards this year and, most importantly, to wish all our readers and their family the best wishes for the holiday season and for the new year.

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25th Anniversary
1971-1996

LETTERS

More On Alternative Treatments

Thanks for your introduction of the subject of alternative treatments in your August 1996 issue. I would like to see a discussion of sensory integration therapy. My daughter, who has autism, received some relief from the sensory aspects of her condition that helped her behavior. An important aspect of alternative treatment that needs to be included is the fact that medical insurance does not cover these treatments, which can be quite costly.

I would also like to see a discussion of bright light therapy for winter depression (also known as seasonal affective disorder). This is not in the category of alternative treatment. The subject has been discussed in many journals across the nation.

It is difficult for children with disabilities to get treatement for this form of depression as a whole. But this is also a care-giver issue. In the search letter entitled "Undiagnosed Neuromuscular Disease" in August 1996, for example, the parent mentions a change in sleep pattern in November. This is one of the symptoms of winter depression. As you well know, when it is difficult or impossible for a child to sleep, the caretaker's sleep and ability to cope is also severely compromised.

J.M., Oregon

I was pleased to learn in your August issue that you were interested in writing about new and alternative approaches to treating various afflictions. My son is four and suffers from cerebral palsy. Here in Europe, Peto therapy (a.k.a. conductive education/therapy) is becoming increasingly popular. Hundreds of international families regularly make trips to Budapest, Hungary, to attend the Peto school that specializes in working with children with brain injuries. They are reportedly very effective.

I am an American citizen and would be extremely grateful if you would extensively report on this approach to working with cerebral palsy kids.

G.D., Germany

Excluding Home Schooling?

Let me begin by saying what an overall great publication you have! But, you dropped the ball in your September Education issue. You've stated in the past that you are about choices for parents. Well, as one letter writer noted in a past issue, you forgot about home schooling. It seems you glaringly overlooked this choice in your education issue, while a number of articles expressed the virtues of inclusion. This leaves parents feeling that if they don't include their child in a school setting, they aren't doing the best for him or her.

For shame! Home schooling can be—and is—every bit as appropriate a setting as a traditional school to meet the educational needs of children with special needs.

I sincerely hope you don't continue to leave out the option to home school our children. It may not be as "easy" as letting someone else educate our children, but it often can be the most rewarding, for both parent and child.

D.G., South Dakota

EDITOR'S NOTE: EXCEPTIONAL PARENT attempts to objectively show parents all educational options. Although we briefly mentioned home schooling in the September and October issues, we plan to discuss this topic more extensively in the coming year.

Sex Education

I am the parent of a 12-year-old boy who has autism and mild mental retardation. I am on the site-based

continued on page 6

You are:

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LETTERS

continued from page 5

team at his special middle school.

At our last meeting, there were concerns about sex education. My son has the comprehension level of a first-grader, but he is experiencing adolescent feelings and urges.

We were wondering if you or your readers can recommend programs for our children. We would like to give them basic understandable lessons on topics such as hygiene, growth and development and "good" and "bad" touches. This could be included with their other life skills training so they can enter society appropriately and safely.

S.V., New York

Editor's Note: Our 1997 July "Teen" issue will focus on these issues, as well as helping your child become independent. Look in coming months for topics on making friends, self-esteem and safety.

We encourage letters from readers on any subject. Letters should be sent to: Letters, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax). Published letters may be edited for space and clarity. Unless otherwise requested, writers will be identified only by initials and state. Please indicate if you would prefer to be identified by name and state or by name, city and state. Please include your full name, address and daytime phone number with every letter; this information is not for publication but enables us to contact letter writers directly if necessary.

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Write to: *Readers Talk, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax). A sampling of reader responses to this question will appear in a future issue.*

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SEARCH

Late diagnosis

Fourteen years ago, just out of the Navy, I gave birth to Dawn. We had some problems during delivery and I was given an emergency c-section. Afterwards, Dawn was taken to intensive care. The hospital staff wasn't very forthcoming, and I wasn't sure what was being done to her.

When I brought Dawn home, things progressed normally. She crawled, then walked—all at a normal pace. Then she started losing skills. Around her fourth birthday she had lost all speech capabilities. Until then, I had no idea anything was wrong. She is now diagnosed with autism and moderate-to-severe mental retardation.

My family and friends think back to the way I was treated by the hospital staff and wonder if there was any malpractice involved. A local attorney investigated the possibility of a suit. His investigation team advised against it, saying the required statutory notice was not filed within two years of the occurrence, making the claim invalid. I was told, however, that other attorneys may have a different view.

I didn't know anything was wrong with Dawn in those first two years. By the time I had addressed my own issues concerning her disability, she'd hit puberty. If there was any malpractice, I think the hospital should be held accountable. I am looking for someone to help or guide me to the appropriate advocate. Other children born in civilian hospitals have until age twenty-one to file a malpractice claim. I think my daughter should have the same advantage.

J.J., Washington, DC

EDITOR'S NOTE: The National Association of Protection and Advocacy Systems in Washington, D.C. may be able to assist you. Contact this organization at (202) 408-9514.

Keeping an eye patch on

My daughter, Genevieve, is three-years-old and has Down syndrome. Her right eye is nearsighted and lazy. Her left eye is farsighted. Her ophthalmologist said she must wear glasses and a patch over her left eye.

We have had no luck with either one. We are getting a contact lens for her right eye, but she must wear a patch over the left. We have tried praising her for wearing it, yelling if she takes it off, holding her hands, but as soon as we turn our backs she rips it off.

She could lose her eye if she doesn't wear the patch and we cannot reason with her. We are desperate to hear of any ideas or suggestions that anyone might have. Please keep in mind that Genevieve has very sensitive skin.

K.V., Pennsylvania

continued on page 46

Search and Respond is an opportunity for our readers to exchange information about their practical experiences meeting the everyday challenges of life with a child or adolescent with a disability. We also expect parents to ask appropriate professionals.

Please indicate whether the letter is a search or response. If a response, be sure to note in which issue the original Search letter appeared. All responses are forwarded to the writers of the Search letters; some are published. Published letters may be edited for purposes of space and clarity.

Write or fax: Search or Respond, *EXCEPTIONAL PARENT*, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570. For information about specific disabilities, contact the National Organization for Rare Disorders (NORD), 100 Rt. 37, PO Box 8923, New Fairfield, CT 06812, (800) 999-6673, (203) 746-6518 (http://www.NORD-RDB.com/~orphan). Also, see "National Resources for Specific Disabilities and Conditions" in *EXCEPTIONAL PARENT'S 1996 Resource Guide* (January 1996).

The National Parent-to-Parent Support and Information System (NPPSIS) is a not-for-profit service that keeps track of children with diagnosed and undiagnosed disabilities whose parents are looking for a match. Parents are matched with a "veteran parent," who has an older child with a similar condition and who is willing to provide guidance and support. Contact NPPSIS, P.O. Box 907, Blue Ridge, GA 30513, (800) 651-1151 (V/TTY) or (706) 632-8830 (fax).

EXCEPTIONAL PARENT
The Magazine for Families and Professionals

Editorial Mission

- *To reach out to mothers and fathers of children and young adults with disabilities and special health care needs*
- *To empower parents and professionals by providing practical information and emotional support*
- *To appreciate that parents are the most important experts in the lives of their children*
- *To energize parents and professionals*
- *To share ideas and experiences so parents, professionals, people with disabilities and other advocates can learn from one another and better collaborate to serve all children and families*

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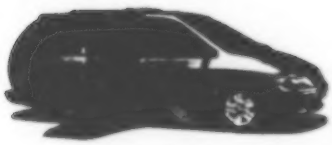

Caravan Entervan® - newly redesigned for '96 and featuring Chrysler's driver-side sliding door.

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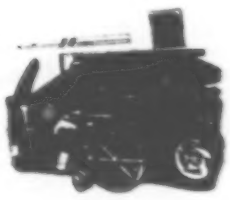

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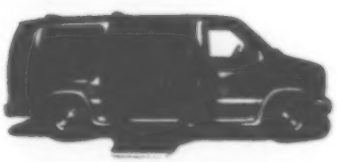
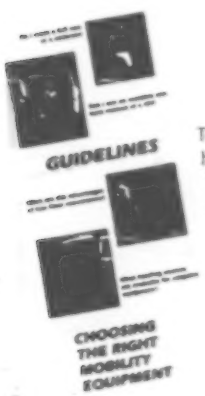


Lift-A-Way® D/C Lift - the latest in Braun's line of personal lifts featuring the ARS (Automatic Roll Stop).



To answer your mobility questions, Braun has published a helpful pamphlet entitled "Guidelines." If you are seeking an adapted vehicle, this is an excellent resource for equipment selection and funding sources. All motor vehicle rebates are also listed. "Guidelines" is available at no charge by calling Braun toll free at 1-800-THE LIFT.

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RESPOND

Moebius Sy..drome?

F.P. and J.P. (September, 1996) have a daughter with an undiagnosed feeding disorder. She has low muscle tone, no facial expression and minimal gag reflex. Having recently allowed placement of a gastronomy tube, they are looking for parents who share their experiences.

I am responding to your letter regarding you daughter, Jessica. Your description matches almost every baby with Moebius syndrome!

We started the Moebius Syndrome Foundation in 1991 when my son, who also has Moebius syndrome, was one year old. Now we have over 700 people on our mailing list from all over the world. We print a newsletter four times a year.

You are probably finding that Jessica's low muscle tone is getting stronger as she gets older. She will walk one day! Her lack of facial expression and inability to suck and difficulty swallowing are due to the lack of the 7th cranial nerve. People with Moebius syndrome also have the 6th nerve affected and therefore do not blink their eyes or move them laterally.

V.M.
Pilot Grove, MO

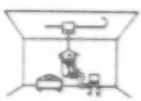
EDITOR'S NOTE: For more information, readers can contact Moebius Syndrome Support Group at 39521 Rowen Ct., Palmdale, CA 93551, or call (805) 267-2570.

Duplication 3q

L.T. (February 1996) is the parent of four-year-old, Isaac, who has duplication 3q (duplication of the long arm of the third chromosome). He has seizures that are almost fully controlled, a visual impairment and global developmental delays. Unlike most children with this disorder, Isaac has only mild heart and kidney defects. He has outlived most reported cases of duplication 3q, leaving doctors little to go on in making a prognosis for future development. L.T. wanted to hear from parents of similar children, particularly those with feeding, sleeping and socialization difficulties.

When my *EXCEPTIONAL PARENT* arrives in the mail, I always set it aside and wait until I know I will have at least one uninterrupted hour to soak in a hot tub with lots of bubbles and savor each letter and article. This month, just as I was starting to read "Search," there you were! Well, some things are just more important than a good "soak." Down the drain went all that soothing, hot, bubbly water, and out came pen and paper.

I also have a son with duplication 3q. He is seven-and-a-half years old, forty-four inches tall and fifty-one pounds. Toby came into this world as my grandson, but he has always lived with me and I adopted him before he



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Circle #37

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was three years old. My daughter was just shy of 17 when Toby was born, and his condition was more than she could deal with at the time.

Toby seemed perfect at birth. But when he was three hours old, the nurse trying to take his temperature discovered he had no rectal opening. Toby was rushed to the neonatal intensive care unit. The doctor explained that Toby needed surgery to open his rectum or he would die.

As I was trying to recover from this shock, the nurse came in to label Toby's crib; I noticed that the label listed a different mom, different birth weight and different birth time. I quickly corrected the mistake. Toby might have some problems, but there was no way anyone was going to switch this baby. I didn't care what Toby's future held; he was ours!

Toby had his first surgery at twenty-four hours old, which was when I had my first foreign-language lesson—Medical Terminology 101. Our lives quickly became a world of doctor visits, hospital stays and words I couldn't spell. In addition to his imperforate anus, Toby had patent ductus arteriosus (a condition in which oxygenated blood flows back to the lungs rather than to the rest of the body), a ventricular septal defect (a hole in the wall separating the left and right ventricles of the heart) and an atrial septal defect (a hole in the wall separating the left and right atria of the heart). Toby also had a neurogenic bladder that retained urine (requiring catheterization every three hours, around the clock), hypospadias (a condition in which the urethral canal opens on the undersurface of the penis, before reaching the tip), a tethered spinal cord and a life-threatening Arnold Chiari Type I malformation of the brainstem.

Toby had a mild stroke at seventeen months, at which time he stopped talking and eating. Previously, he had been eating a predigested formula and baby food. He now has a permanent gastrostomy tube. The only thing Toby will eat orally today are things that are dry or salty like chips, french fries or dry breaded foods.

Toby has developmental delays in all areas. He has had two years of early intervention, three years of preschool, one year of kindergarten, and is about to finish first grade. Toby is partially included in a regular first grade class, but he learns more during those periods in which he is pulled out for one-on-one tutoring. He also gets occupational, speech and physical therapy. He is starting to read; he is also doing math.

We don't have a prognosis for Toby's future, either. We try to take things one day at a time and treasure every moment we have with him.

J.Y., Arizona

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Circle #16

Familiar Faces

Kelsey Rae Easterwood, 3 1/2, loves school! Her speech therapist works with her every day and she can say words like "apple," "mom," "hi" and "hair." Kelsey was born with a heart murmur and at three months was diagnosed with Williams syndrome, which includes heart abnormalities. Her mother, Karen, says she is very proud of her daughter. Kelsey lives in Reading, Pennsylvania, with her mother and father, big sister, Ryan, 9, and twin kid brothers, Eric and Matthew, 2 1/2.

Seven-year-old **Michaella McGee** (center) is a first-grade student at Benton Elementary school in Benton, Maine. She lives at home with her parents, Mike and Kathy, and her two sisters, Jamie (left), 10, and Haley (right), 4. Michaella is diagnosed with mental retardation, pervasive developmental disorder and autism. She loves music, Big Bird and eating all kinds of foods. Her parents say that Michaella is an angel sent to them from Heaven to enlighten their lives and spread love throughout the family.

***Would you like to share a favorite candid snapshot or slide** of your child and/or family with other readers of EXCEPTIONAL PARENT? Send it to: Readers' Photos, EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517 (Sorry, photos cannot be returned). On a separate sheet of paper, write your child's full name, age at the time photo was taken, address and daytime phone number, and identify everyone in the photo. If you like, you can also write a few sentences about your child. Then look for a familiar face in an upcoming issue!*

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Nicole Hofhine, 2, goes barefoot in the grassy backyard of her home in Camarillo, California, where she takes a minute to pose for the camera. But only for a moment! Nicole, who has osteogenesis imperfecta (brittle bone disease) and cannot walk, loves to ride her toy car and her mother, Michelle, says that nothing stops her. Pedestrians, beware!

Sitting with his big brother, Aaron (left), 10, six-year-old **Brandon Jamaal Jones** (right) plays with his newborn brother, Cameron. Brandon has been diagnosed with static encephalpathy, and even though he cannot speak, his beautiful big eyes say it all. Brandon lives with his brothers and parents, Valor and Anthony, in Fort Bragg, North Carolina.

Vincent John Kalishes IV holds his head high as he shows off his brand new walker. At 11 years old, Vincent lives in Scituate, Massachusetts with his parents. He is non-verbal, cannot walk independently and has hearing and visual impairments. His father, Vinny, says "He is the apple of his father's and mother's eyes, a joy to be around and to learn from."

The result is a group of women who are more accomplished and confident with each passing day.

We have a few spots open and look forward to adding new members to our family. If you know an exceptional woman who could benefit from all that Riverbrook has to offer, call for a brochure. Or better yet, come up for a visit. 1413 298-4020

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McDonald's Special Ingredient:

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When McDonald's opened its first restaurant in the 1950s, our goal was to become a national operation, yet remain everyone's friendly and familiar neighborhood restaurant. That means never forgetting that people are the essence of our business.

"We have an obligation to give something back to the communities that give so much to us." Those words from McDonald's founder, Ray Kroc, have guided us since the beginning. McDonald's—now a global operation— sponsors everything from high school bands to wheelchair sports day camps. Our programs are national and local and they share a common goal: to give everyone an opportunity to succeed.

As one of the nation's largest employers, we're proud that we can provide opportunity to a work force as diverse as America itself. We've had the privilege to be the first employer for countless young people, and to offer an alternative to people over 55 who aren't ready to retire from an active lifestyle. Our employees also include moms and dads who want to earn some extra money, and college students on the brink of a career. And, yes, many of our McFamily members are people with disabilities.

At McDonald's, focus on abilities, not disabilities. That's why we created the McJobs program to provide opportunities for people with disablities. Since 1981, more than 12,000 men and women have successfully completed McJobs training and gone on to become restaurant employees. Today, nearly 75 percent of McDonald's restaurants employ at least one person who has a physical or mental disability. We recognize that everyone deserves the chance to take pride in a job well done—and we're proud to be able to provide those jobs.

Offering opportunities to qualified people who may have a physical or mental disability is good people sense and good business sense. We've learned that the disability is often far less disabling than the obstacles society has put in the way.

Giving people the chance to simply be included is not a mystical or complicated process. Our many customers with disabilities have taught us that. Since 1976, McDonald's restaurants have been built to prevailing standards for accessibility. Older restaurants are renovated in the regular course of remodeling. In 1979, McDonald's was one of the first companies to begin offering Braille menus. Picture menus are also available for our customers with speech or hearing impairments.

McDonald's also was one of the first to integrate people with disabilities into TV commercials. In fact, the 1986 "Silent Persuasion" commercial portraying a young couple with hearing-impairments was the first TV commercial produced completely in sign laguage.

The Ronald McDonald House provides families of seriously ill children with a place to stay. The Ronald McDonald House Charities have given more than $63 million to support the efforts of organizations around the country that are providing opportunities to people in their communities—speech and hearing clinics, rehabilitation and independent-living centers and other programs.

As we look ahead to the year 2000, it is our hope that all of us can come together to more fully live out the promise of valuing diversity by making sure opportunity is there to everyone who wants it. People are our most valuable natural resource. The more we give each person the opportunity to succeed, the more we all succeed.

McDonald's is honored to receive this award and be named a Corporation That Cares. And we congratulate Exceptional Parent on its 25th anniversary and commend the magazine for its efforts to teach this simple truth: It's not about a person's disability at all. It's about ability and the opportunity to let it grow.

We know the true winners are those who simply want an opportunity to succeed, and those who give them the chance. **EP**

In collaboration with the National Organization on Disability, EXCEPTIONAL PARENT is honoring corporations that provide employment opportunities to people with disabilities, support the participation of these employees in everyday corporate life and feature people with disabilities in advertising programs.

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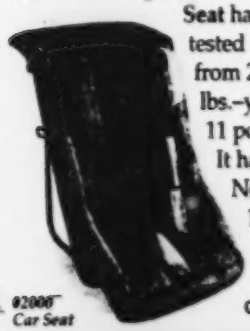

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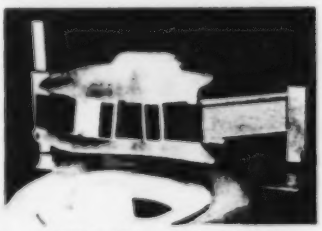

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Like other children all over the world, residents of Berkshire Meadows attend "school" (our Learning Center) five days a week. Each follows his or her own curriculum, designed to respond to individual needs: physical development, cognitive development (based on Piaget), the use of basic living skills. Our program for young adults also includes Applied Academics: techniques such as the use of money, and basic computing. And as a corollary to the Total Communication techniques we apply throughout our program, all students participate in Augmentative Communication training, where individual methods of communication are developed.

The young people live in spacious one-story homes, each with its own lounge, visiting area , kitchen, dining room, laundry and specially-equipped bathrooms. Each youngster has a bright, attractive bedroom, and is encouraged to keep personal pictures and toys. Here, in an atmosphere of nurturing home life, each resident learns about self-care and daily living skills, and staff accommodate personal needs with respect and tenderness.

Each resident of Berkshire Meadows follows his or her own individualized physical therapy program. We take full advantage of all the tools and techniques that research and modern technology have provided to ease pain, relax muscles, develop strength and expand movement, including extensive hydrotherapy. Specialists in the fields of psychiatry and psychology work with the young people to promote emotional and mental well-being. Round-the-clock nursing coverage ensures that each child's physical needs are constantly and consistently monitored.

Weekends and holidays are for fun. We take full advantage of the loveliness of our natural surroundings, and of the receptive friendliness and extensive activities of local communities.

Our intent is to help "our" young people to become more independent, more self-sufficient and empowered. For their families we strive to offer education, encouragement and support. We believe that with thoughtful, cohesive integration of specialized education and physical care, and family and community support, each child has the opportunity to achieve his or her maximum potential, and, most importantly, to experience satisfaction and joy.

Berkshire Meadows
Gail Charpentier, Exec. Dir.
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SUPPORTIVE HOUSING

Living and Working in a Rural Neighborhood

A new option for Iowans with autism

by Sally Pederson

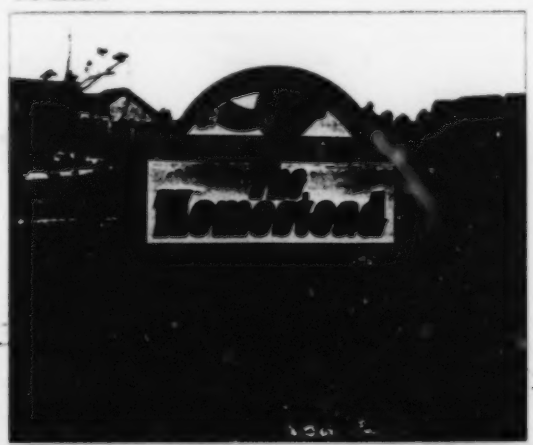
The Homestead was founded by the grassroots efforts of parents and professionals who recognized the need for a provider agency with a primary focus on autism. As recent as twenty years ago, the vast majority of people with autism were placed in state institutions.

Over the last decade, services for children with autism have improved as knowledge has increased. Today, with early identification and appropriate interventions, children with autism are able to take advantage of both special and general education opportunities.

Unfortunately, services for adults with autism lag behind. In most states, adults with autism have few residential or vocational options available. They usually fail in typical programs designed to serve those with mental retardation because they need different specialized supports. Those who do not start out in institutions, usually end up there.

The greenhouse at The Homestead offers employment opportunities for residents.

The Homestead first opened in 1995 for teens and adults with autism.



Creating new options

In 1991, a group of parents and professionals in Iowa came together to create new living and working opportunities for adults with autism. They looked at other programs around the country and talked with experts in the field of autism, including Bittersweet Farms (Whitehouse, Ohio) and the Carolian Living and Learning Center (Chapel Hill, North Carolina).

From these efforts, The Homestead was founded. A nonprofit organization, it set about to create a model program for Iowans with autism. With a strong board of directors and an advisory committee of community leaders, plus a solid

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vision and a worthy mission, the founders set about raising both the public awareness and the dollars necessary to support their vision.

In January of 1995, The Homestead opened the first of six four-bedroom homes on 80 acres of farmland just outside Des Moines. Today, 20 men and four women, ranging in age from 16 to 42, live and work there. Eight of the residents attend high school. The others work winter months in the greenhouse, and spring and summer months in the produce gardens. The Homestead supplies spring bedding plants to local nurseries and sells summer produce at area farmers' markets. From August to December, the greenhouse nurtures 1,000 poinsettias for wholesale distribution to local fundraising groups.

The Homestead is a licensed intermediate-care facility for the mentally retarded and receives funds through federal, state and county tax dollars. Though this level of support is expensive, it is less costly than institutional care and provides residents with a far more normalized living and working environment.

FOR MORE INFORMATION WRITE: THE HOMESTEAD, 8270 NE 12TH STREET, RUNNELLS, IOWA 50237.

The Homestead also provides services to children and adults with autism in their homes and communities through the Home and Community Based Services waiver. Through this outreach program, a person with can receive the services and supports needed in order to continue living within the family or community.

The staff who work with residents and the staff who provide outreach services receive extensive training. This specialized training is the key to helping children and adults with autism succeed in the school, home, workplace and community. Certainly—with the help of The Homestead—they do in Iowa.

Sally Pederson was the founding President of the Board of Directors on The Homestead. She is the mother of a 13-year-old son with autism who lives at home with his parents.

Persuing Self-Determination

by Donald J. Shumway and Thomas Nerney

We have all been in the position of pursuing self-determination—knowing our own needs best—and yet having to give up control to experts. The movement is growing for self-determination as a government and institutional policy for allowing people with disabilities to determine their own futures. It derives from the belief that all persons—including people who have disabilities and their families—deserve that opportunity. No one does a better, or less costly, job at that than those who are most affected.

Interpersonal relationships, learning and community roles all suffer under programs that "provide for" but do not encourage self-direction in one's own life. With self-determination, we can dare to dream.

Self-determination is an important next step in how services will be delivered, allowing persons and their families and friends, in conjunction with professionals, to be the decision makers concerning the needed supports.

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Examples of self-determination

The most innovative self-determination initiatives are those in which persons and families determine how an individual budget will be spent on housing, employment and personal needs. An important feature of this approach integrates persons with disabilities in the life of their communities and builds informal networks of friends and family who can provide some of the necessary day-to-day support. For example, a person with a disability may make a suitable arrangement with co-workers for transportation to employment rather than use a separate transportation system for people with disabilities. In this way, the quality of life for persons with disabilities can be enhanced and expenditures may be reduced.

Many persons and their families have been clamoring for such an opportunity for years. This type of change started with good family support programs that gave over the reigns of bureaucratic structure to families in areas such as family-controlled respite care. Families are now looking beyond respite and calling for a more sweeping commitment, including features such as:

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Taking Charge of Our Lives
A parent's experience

by Donald L.Shumway

It has been so easy for the world to look at persons with disabilities and tell them what they can not do. Our son had been labeled as learning disabled since first grade, but it was when he first entered adolescence that his school began talking in terms of his failures and shortcomings. Cute and pleasant did not make it any more. Learning disabilities were the issue.

After several more years of being measured on his lack of academic success, the school began to tell us the problem was that he was just not motivated. What could be expected after years of being told you do not measure up?

As parents, we knew better. It was as if we had two different kids. The one at home was happy, always busy doing incredible things with his computer and willing to try anything new. The one at school (but for a very special teacher or two), was silent, angry, and unwilling to do anything. That was the point at which my wife and I—and most importantly, our son—said "enough."

At that point, we stepped back from the "system" and began to write our own I.E.P.s. We changed schools and let our son's interests be the driving force in selecting the classes that made sense. We worked hard to connect him with the right teachers. Now we have our old son back—at school, as well as at home. We are lucky that we did not lose him to the frustration and failure. Just in time, we took charge of our lives. We started practicing for ourselves what some are now calling "self-determination."

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Your Child Is An Adult— What's Next?

All parents want their children to lead active, productive, well-balanced, happy lives. Will that describe life for your young adult with disabilities after high school? Will your son or daughter continue to build a positive self-image? Will he or she have the opportunity for training, joining in peer groups, enjoying and benefiting from leisure activities? Will your child continue to discover and develop interests and talents, take pride in accomplishments, gain purpose and direction and lead a more adult, responsible life?

All young adults and their families are faced with decisions about life after high school. But when a young adult has developmental disabilities, considering changes, exploring options and making decisions can be more difficult.

Since 1969, the Annandale Village community has offered options caring parents want for their children, options that are not always available—or even considered realistic—to many adults with developmental disabilities.

It Takes a Village

When the Village concept was first developed more than 27 years ago, the goal was to provide opportunity, growth, dignity and independence for its residents. The programs and services are designed to offer men and women with developmental disabilities an improved quality of life, both within and outside their Village community. The Annandale Village environment is as close to community inclusion as possible, giving each person the freedom and stability to be the best he or she can be. These programs include:

- vocational training
- job placement
- creative and performing arts
- recreation and leisure activities
- skills training for Special Olympics
- daily living-skills instruction

Annandale offers both residential and non-residential services and programs that offer a balance of structure, freedom, encouragement, instruction and fulfillment individualized for each resident. The residents of Annandale Village are afforded an opportunity to share—many for the first time—the benefits of caring and nurturing friendships that will last a lifetime.

Full residential care includes housing, house parenting, nutritionally-balanced meals, case management, on-campus health services, medical monitoring, counseling and off-campus transportation. The secure, 136-acre environment includes a farm, 15-acre lake, nature trails, outdoor swimming pool, softball field, accessible gym, art gallery and a sheltered workshop.

Each resident's schedule is designed to meet their individual needs with an equal balance of work, play and socialization. Most importantly, each is given the opportunity to acquire new skills, resulting in a sense of accomplishment and pride many may feel for the first time.

Training and instructional programs are included in both residental and nonresidential programs. Activities such as Special Olympics, staff/villager softball games and field trips, and particiaption in many activities available in the Atlanta area, add both challenge and fun to the daily lives of Annandale clients. A professional staff member actively seeks corporate and personal contributions and donations that provide a steady stream of complimentary tickets to sporting and cultural events. The wide range of field trips available provide recreation, creative stimulation, socialization and integration outside the Annandale community.

Through an optional workshop program, clients may participate in on-site job training, including employment in the sheltered workshop which contracts with private industries. As Villagers develop proficiency through the Annandale programs, they are recommended for paid and volunteer positions in nearby communities, with transportation provided by the Village. Classes for adjusting to work environments are provided for all off-site workers, with training in areas of employer/employee relations, appropriate behavior and other job-related skills.

Annandale Living

All on-campus residences are designed to promote physical and emotional well-being and to create an environment that is comfortable, attractive, familiar and secure. Cottages, suite apartments and studio apartments provide living arrangements appropriate for men and women of varying abilities levels. All accomodations include common areas for shared in-house activities.

Berry Hall is the food services center where staff members prepare and serve three meals a day, every day of the year, as well as for traditional holiday meals and special events. House parents play an important role in supervising, monitoring, guiding and creating a consistently warm, supportive atmosphere. There are also several staff residences on-campus.

Full-time medical personnel are staffed to care for the health of the Villagers. They treat minor ailments and manage and schedule all medical appointments.

Annandale Village is a private non-profit 501(c)(3) corporation located just 30 minutes northeast of Atlanta, Georgia. For more information, please call or write: (770) 945-8381, 3500 Annandale Lane, Suwanee, Georgia 30174. **EP**

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Giving each person the freedom and stability to be the best that they can be... Annandale Village

✦ Our Mission ✦

Annandale's mission is to perpetuate a private, nonprofit Village community offering adults with developmental disabilities an improved quality of life. The Village provides professionally managed and cost effective lifestyle alternatives through specialized programs and services flexible enough to meet individual needs . . .

Their Community With Our Help.

✦ The Annandale Story ✦

Annandale Village provides a natural and serene environment for adults with developmental disabilities. Annandale began through the concern of Dr. and Mrs. Maxwell Berry for the future and welfare of their child with developmental disabilities. They wanted what all parents want for their children in adulthood. . . the opportunity for the best life possible. But for the Berry's child and others with similar disabilities, future options and opportunities were very limited.

Dr. and Mrs Berry traveled extensively in the United States and abroad, studying facilities for adults with special needs. They believed that the European concept of a village community could be successfully adapted to create a desirable and beneficial alternative to institutionalization and community inclusion.

Incorporated in 1969 as a 501C(3), Annandale Village is now located on 136 acres in Suwanee, Georgia, just 30 minutes north of Atlanta. The village setting is one of natural beauty and peace among rolling hills, woodlands, pastures, orchards, vineyards, a farm, and a lake.

✦ The Sheltered Workshop ✦

The Sheltered Workshop is a vital part of Annandale's paid vocational training program as well as an integral aspect of the Annandale concept. Workshop employment provides a source of income for many Villagers and serves as preparation for job placement outside the Annandale community. The sheltered workshop operates on a contract basis with local businesses, can perform a wide variety of jobs, and has a history of excellent quality control. References are available upon request.

✦ Our Programs ✦

- *Paid Vocational Training and Job Placement*
- *Creative and Performing Arts*
- *Recreation/Leisure activities with skills training for Special Olympics*
- *Daily Living / Life Skills*

✦ Annandale Services ✦

Full Residential

- Cottages, semi-independent and independent apartments accommodating 102 residents
- Nutritionally balanced meals served in the Village cafeteria
- House Parenting
- Case Management
- On-campus Health Services
- Medical Monitoring
- Counseling
- Off-campus Transportation

Non-Residential Day Programming

- Appropriate services and training, including case management, are provided based on program participation.

Campus Environment

Programs Center with collegiate size, handicapped accessible gym, art gallery, sheltered workshop, and components for arts activities, educational support and recreation.

✦ Enrollment Eligibility ✦

Individuals must be 18 years of age or older and ambulatory with a primary diagnosis of mental retardation, developmental disabilities, or head injured. Other diagnosis will be evaluated.

Photos by Eagle's Cry Productions, Inc.

Annandale
VILLAGE

3500 Annandale Lane
Suwanee, Ga 30174
770-945-8381

Certified by IRS as a private, 501 (C)(3) Nonprofit Corporation. Georgia Permit #067-03-001-01
Charitable Registration # 01-911713

Circle #43 1068

Principles of Self-Determination

- Freedom.
  - To Plan a Real Life
- Authority.
  - To Control a Limited Amount of Resources
- Support.
  - For Building a Life in One's Community
- Responsibility.
  - To Give Back to One's Community

• Individuals and families controlling a specified amount of financial resources—an individual budget—so that they can directly purchase or arrange desired and necessary education, day, or residential supports;
• Individuals and families planning their own futures with assistance from family and friends as well as others whom they determine helpful, as opposed to just responding to the sometimes "computer-generated" and often irrelevant Individual Service Plans (ISP), Individual Education Plans (IEP) and Individual Treatment Plans (ITP).
• Helping persons with developmental disabilities inform other persons with disabilities about how they can live more independently, and introducing families to the new opportunities available under a reformed system (for example, how flexible funds can support community living);
• Creating agencies (either by changing present ones or starting new ones) that become fiscal intermediaries and personal brokers to back up and support families with services such as payroll, insurance and related assistance;
• Making sure that managed care does not become an impersonal corporate management system, but rather a person-directed support system.

Steps in Self-Determination

1 An Individual Budget.
2 A Caring Social Network.
3 Brokered Supports.
4 Investing Closest To Home.
5 Joining Community Organizations.

Robert Wood Johnson Foundation
The Robert Wood Johnson Foundation (RWJF), the largest U.S. philanthropy devoted to health care, has created its first national program devoted to people with developmental disabilities: "Self-Determination for Persons with Developmental Disabilities." RWJF will distribute five million dollars in grants to help state governments change their policies to support self-determination.

Its exclusive aim is to help individuals and families gain this new strength for taking charge of their needs. Having supported the testing of such projects in New Hampshire and observing similar efforts in other states, RWJF has established a National Program Office at the Institute on Disability at the University of New Hampshire under our. The office will provide technical assistance through such services as consultation and education. Twelve states will be chosen to work with the foundation in transforming their service delivery systems into community support systems that facilitate self-determination. In applying for the program, states are expected to show how existing resources will be reallocated, and how these reforms will enable more people to be served with existing resources. This national project occurs at a time of historic change in federal and state public policy for the health care and social service needs of vulnerable populations. Emphasis on balancing the federal budget and pressure from increasing service demands are leading states to reconsider their basic organization and policy in this arena. This RWJF initiative will give states and families an important tool to move forward rather than slide backward into uninformed cost cutting.

The states respond
State applications, thus far, reflect how, under their future policies, persons with developmental disabilities and their families will gain control over their supports.

Most of the state applications being reviewed reflect an intense planning effort that draws together individuals with disabilities, their families, providers, various state agencies, advocates and others. The most frequently requested support is for training, particularly in techniques of "person-centered planning," "circles of support" and related efforts that give access to advice and counsel on personal future goals and steps needed to achieve them. Many applicants have focused on helping develop personal budgets or resource packages. A few proposals describe how they would assist or broker supports—especially natural, community supports—and how individuals would be assisted in participating in valu-

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able roles in their neighborhoods and in community organizations.

Overall, the states are trying to focus public funds on supporting "real lives" rather than regulation-dominated programs. They are also working to produce some cost savings so that the waiting lists for services can be reduced (RWJF funds cannot be used for direct services).

Don Shumway was the Director of the New Hampshire Division of Mental Health and Developmental Services for more than twelve years. He directed the closing of the Laconia State School, enabling New Hampshire to become this country's first state relying solely on community-based support services. Recently, New Hampshire earned top marks from the ARC for its highly integrated, small scale residential supports as well as its supported employment programs.

For many years, Tom Nerney has worked with advocacy organizations and states to assist persons with disabilities in gaining their rights and taking their place in our communities. Over the past three years, Tom has been responsible for implementing a local initiative in the Monadnock area of New Hampshire, which applied self-determination practices.

FOR MORE INFORMATION, WRITE DONALD J. SHUMWAY AND THOMAS NERNEY, INSTITUTE ON DISABILITY, UNIVERSITY OF NEW HAMPSHIRE, THE CONCORD CENTER, 10 FERRY STREET, UNIT 14, CONCORD, NH 03301-5019.

OWNING OUR OWN HOME
A New Model for Independent Living

by David and Margot Wizansky

Adapted from the original article,, which appeared in Exceptional Parent, December 1985.

Over the course of more than 20 years of working with people with developmental disabilities, it became clear to us that most were living lonely, isolated lives. Those living independently or even in an agency or state-supervised setting were often subject to the whims of a landlord or agency or public policy, creating great insecurity for them and for their families. They are never fully integrated into the social life of the community, nor are they considered fully-participating citizens. We wondered whether property ownership in a community of their peers would improve any of these conditions.

In the last three years, we have facilitated the development of 22 units of condominium housing for adults with developmental disabilities in Brookline, Massachusetts. This was a joint venture of parents and residents with considerable help from an architect/developer and an attorney. The units are located in two large Victorian-style houses, each within walking distance of more than a dozen stores, as well as public transportation.

Beth Glasky and Stephanie Weaver, residents at Specialized Housing, Inc.

These "chaperoned" condominium boarding

continued on page 28

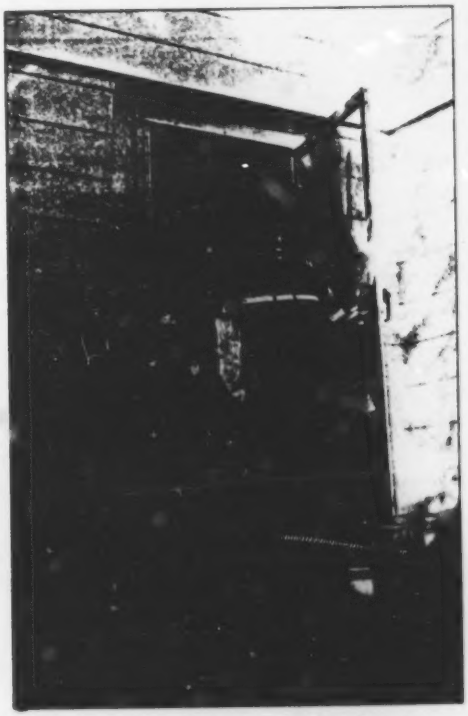
Rob Ritter and Darryl Eldridge, residents at Specialized Housing, Inc.

continued from page 27

houses combine the opportunity for residents (and parents) to own their own homes while enjoying the friendship and support of other unit owners and around-the-clock trained staff.

Community structure

Each resident owns a unit which includes a private bedroom and a share of the common space. Residents share dining, living, recreation and guest rooms, as well as a large kitchen.



Kevin Dyer (on the left) and David Jackson, residents at Specialized Housing, Inc.

All residents are over 18, capable of self-care, free of serious emotional disorders and able to negotiate the community on their own. They are occupied during the day at school, in sheltered workshops, or working in the competitive job market.

When residents are home, an experienced house manager is available for assistance or encouragement. The house manager and other house staff provide supervision in the areas of planning, scheduling, shopping, meal preparation, budgeting, leisure time, personal grooming and care of the house. A staff person who lives in an apartment on the first floor is on call at night and oversees the early morning routine. Staff is there to facilitate independent living, not to provide service to dependent adults.

Residents enjoy the freedom of going out on their own or in small groups with friends from within the house or from the community. Activities are of their own choosing. Though they share a house, each resident has a private room and is expected to respect the privacy and individual differences of housemates.

Almost all residents describe themselves as mentally retarded. Each requires some assistance from time to time, but they are not ready or able to live completely on their own. Most were living at home where they yearned for opportunities for peer socialization and increased independence. At the same time, their parents were looking into the future, recognizing the need to insure ongoing, reliable support for their sons and daughters.

For some residents, their condominiums will be a stepping stone to more independent living situations. For others, it is a permanent home.

Private Resources

The development of these condominiums has been done solely with private funds. Residents and/or their parents purchase the units, making their own financial arrangements. Financially and legally, this development is like any other condominium in the community.

Each resident pays a monthly fee which covers all meals (except weekday lunches), staff, administration, insurance, utilities, real estate taxes, building maintenance and other costs. Owners also make monthly payments for real-estate taxes on their own units and for principal and interest if they have a mortgage.

Some pay their own way with income from employment or government support programs. (Owning property which serves as a primary residence does not affect eligibility for various government support programs.) Others need financial assistance from families.

Owners can benefit from the income-tax deductions available for interest payment and taxes. Far more important, owners are building equity in their own property so they can sell if they decide to move.

We emphasize that housing is the primary service residents are purchasing, and that they are receiving help in managing it themselves.

A nonprofit corporation—Specialized Housing, Inc.—oversees the building and manages the

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UPDATE
The Brookline Experience, 1996.

Today, Specialized Housing Inc. serves 70 adults with different disabilities—developmental, learning, autism, seizure disorders and mental illness—in eight different buildings in four communities. Some individuals are visited by staff in their own separate apartments, rather than community-living homes. [Stan: is this correct?]

Since 1983, some people who lived in the original two houses have moved to their own apartments [Are these the same "some individuals" as above?] For most, however, the community serves as permanent housing.

In October 1996, some of the "owners" who live at the supportive housing program and some parents discussed their wonderful accomplishments with a group of other adult consumers, parents and professionals in London, United Kingdom. It is likely that, soon, there will be similar programs including self-determination and home ownership evolving there.

staff. Each building is owned by a condominium trust and had a lodging-house permit. Many parents are involved in management, continuing their vital role as project founders.

More than just a place to live

Expectations for residents and staff are different from many traditional group homes. Residents are expected to participate in cooking and cleaning teams for the evening meal and be at home for dinner seven evenings a week unless they notify their house manager about other plans. Residents also participate in regular meetings with staff to help with the type of social-interaction issues that come up whenever any group of people live together. They are required to attend a weekly condominium meeting with the house manager.

Staff are expected to serve as resources in case of difficulty, but they do not plan programs or activities. They also do not make decisions for residents, but, instead, encourage self-determination. All the residents have found this a new life experience. **EP**

Margot and David Wizansky, both licensed social workers, founded and developed this project in collaboration with parents. They are the principals of Specialized Housing, Inc., 5 Bartlett Crescent, Brookline, Massachusetts 02146.

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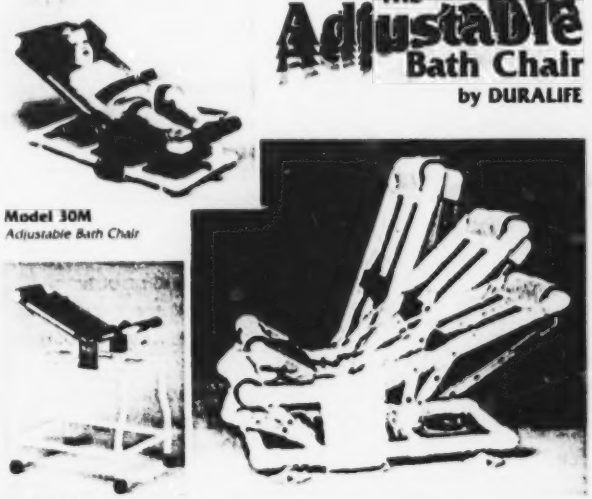

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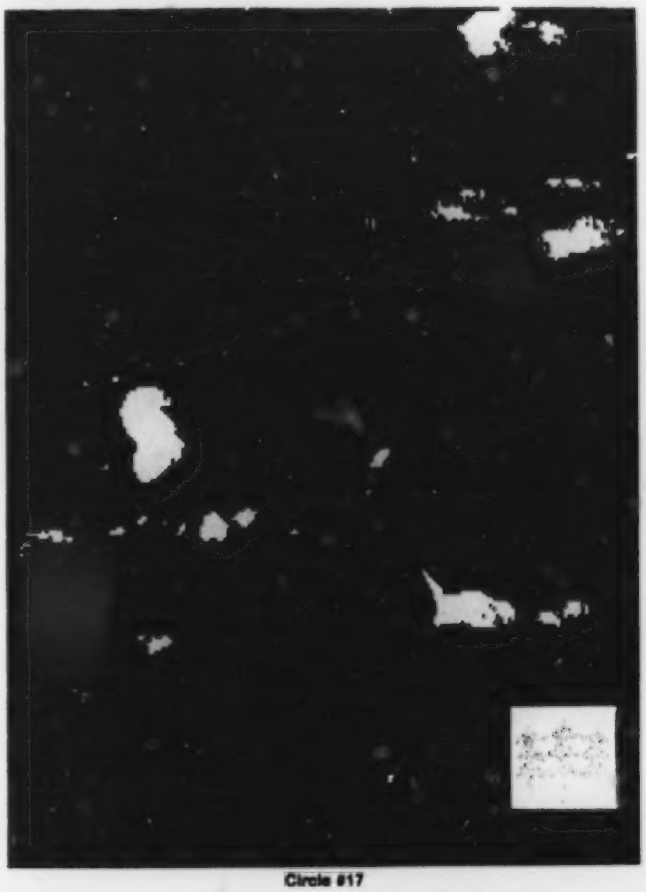

Circle #17

C. Everett Koop, M.D. and Joseph Dutkowsky, M.D. teleconference via Picasso.

TELEMEDICINE

Bridging health care distances for rural families

Ajai Pasupuleti was born with osteogenesis imperfecta—a birth defect causing brittle bones—near the small rural town of Norwich, New York. At 18-months, a thigh-bone fracture required that he be fitted with a correctional brace and kept flat on his back with both legs extended for several weeks. Evaluations and x-rays had to be made every two weeks by a pediatric orthopedic surgeon at Bassett Health-care in Cooperstown, New York, about an hour away from Ajai's home.

Dr. Joseph Dutkowsky with Picasso telephone.

Because Ajai is not able to sit in a conventional car seat and needs an adult to ride in the back seat with him, traveling is hard for him and his parents. Car travel means rigging a padded cardboard box big enough for Ajai and his brace, yet small enough to fit in the back seat of the car. Getting Ajai into the car and making the two-hour round trip to Cooperstown for x-rays and follow-up evaluations are difficult for the family.

Now, a new developing technology is allowing Ajai to be examined and x-rayed by Laura Jean Olivia, a physician's assistant employed by Bassett Healthcare, whose office is in Oneonta, New York, only 35 minutes from the Pasupuleti home. Ms. Olivia can put Ajai's x-ray up on a light box and videotape them with an ordinary camcorder. The image in the camcorder viewfinder also appears on a television screen in her office which is part of an AT&T video telephone called the Picasso™. Next, she makes a call to Cooperstown to alert Ajai's pediatric orthopedic surgeon, Joseph P. Dutkowsky, M.D., that an image of Ajai is coming in. There, an identical Picasso™ unit is turned on and Dr. Dutkowsky and/or other specialists see the same image. Ms. Olivia can talk over the Picasso™ phone with Dr. Dutkowsky about the x-ray, using the Picasso™ mouse to circle and highlight areas that need discussion. Sometimes Ajai's parents take part in the video conferencing. They can explain exactly where Ajai hurts and Dr. Dutkowsky can show them the location of Ajai's bone fractures.

Before telemedicine, Ms. Olivia would have had to make an assumption about an x-ray on her own or mail it to Dr. Dutkowsky for his review. This might require that Ajai and his parents return for additional X-rays and discussion.

By having Ajai x-rayed in Oneonta, the Pasupuletis save additional travel time. Most importantly, they save Ajai the pain of each bump and jolt along country roads.

continued on page 32

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Continued from page 30

Telemedicine network

In Oneonta, Picasso™ gives Ms. Olivia access to a network of over 10 regional medical centers, including three rural hospitals serving 10 central New York counties.

At the hub of this telecommunications network is the Bassett Healthcare campus in Cooperstown, New York. There Dr. Dutkowsky, working with Michael Caputo of the C. Everett Koop Institute at Dartmouth College in Hanover, New Hampshire, developed the network in response to the concerns expressed in focus groups by parents, primary care practitioners and other health care providers.

The primary piece of equipment is the Picasso™ video telephone, which can send high quality color images using an ordinary camcorder, television, and standard phone lines. X-rays, medical records including EKG readouts (which are very difficult to store and send via computer) and other medical information can be transmitted to and from remote health care offices along with video still color images of wounds, rashes, or body areas. The Picasso™-transmitted image is seen on television screens by people at either end of the call who can also speak with one another through the system.

The cost of Picasso™ transmission is the same as a regular phone call to wherever the images and information are sent.

Picasso™ could provide Devin Hamilton with big-city care without going far from his farm.

Only individuals licensed to make medical diagnoses are allowed to use the Picasso™ in the Bassett network. All encounters using Picasso™ are provider-to-provider and informed consent must be given by consumers before images can be transmitted.

Added benefits

Families not only save time and pain; they also save money. For example, eight-year-old Anemarie Wenck of Oneonta, New York, has trisomy 9, a condition that can effect physical growth as well as other aspects of development. The pediatric endocrinologist who has been treating Anemarie since she was 18-months old practices in Brooklyn, New York. He sees her every three months in order to update her growth-hormone prescription. For the four-and-a-half-hour drive, Anemarie's mother must take time off from work and make arrangements for someone to care for her other daughter. The Brooklyn endocrinologist usually writes a new prescription for Anemarie's growth hormone and asks that she be x-rayed and have blood work done, with the results returned to him.

This month, instead of missing work and spending eight hours in the car—and over twenty dollars for gas, plus money for a baby-sitter—Mrs. Wenck can take Anemarie to Cooperstown, only twenty miles from their home, for her blood work and x-rays. The results will then be telefaxed via the Picasso™ to the Brooklyn endocrinologist. Mrs. Wenck can then teleconference with the endocrinologist, and he can prescribe the appropriate dosage of growth hormone.

Future possibilities

Bassett Healthcare is investigating other uses of telemedicine. For example, with special stethoscopes and earphones that plug into the Picasso™ unit, physicians can listen to a geographically-distant individual's heart. Using the video component of the Picasso™, the clinician on the receiving end can see the location of the stethoscope and can watch and listen as it is moved.

Sometimes families of children with disabilities feel pressured to move to metropolitan areas where needed facilities and specialists are more available. With telemedicine, the sense of community can be preserved by bringing crucial information to rural practitioners and consumers, and the distance between specialty hospitals and primary health care providers and families can be bridged. **EP**

For more information regarding the use of this technology for community-based health care for individuals with disabilities and their families write: Joseph P. Dutkowsky, M.D., Bassett Healthcare, One Atwell Road, Cooperstown, New York 13326-1394.

The Bassett Healthcare telemedicine network obtained the equipment described in this article with a grant from the United States Department of Agriculture's Rural Utilities Service Development. An evaluation of the telemedicine network was made possible by a grant from the Office of Rural Health Resources and Services Administration of the United States Department of Health and Human Services.

This article was prepared by Sharon Parmet, an editorial intern enrolled in Boston University's science journalism program.

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Everyday Hero

RICON

A Great Scouting Opportunity.

Troop #767SNS (Special Needs Scouts) of Orange County, CA. is just like any other boy scout troop, except for one thing—every member has a disability. Because most of the boys use wheelchairs, their participation in traditional scouting activities is a major challenge...but one they face with pride and determination. The troop, founded by Bruce Marich, president of Southern California Mobility, is currently raising money to buy a mini-bus equipped with a Ricon lift.

Until then, Bruce's personal van installed with the Ricon S-1231 Clearway Wheelchair Lift is ideal for the troop's transportation needs. Its strong steel frame and powerful hydraulic pump provide a fast, secure means of entry and exit for the scouts. And the fully automatic split platform of the Clearway lift folds up and out of the way, leaving the doorway clear for loading and unloading supplies. We call this the "Ricon Open Door Policy."

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A PARENTS' GUIDE TO ENTERAL NUTRITION
PART FIVE
Why not change to oral eating?

by Debra Beckman and Lee Barks

The move to enteral feeding can be made either as a permanent or a temporary solution to a nutritional problem. Even if begun as a permanent measure, however, health care professionals are being encouraged by parents and other professionals to review the decision in light of new therapy methods, to ensure that it is the best decision for the child and his or her continued development.

The obvious drawbacks of enteral feeding range from social development issues to the simple enjoyment of life. In a growing list of states such as Florida and Tennessee, it has become a human-rights issue as cases are brought to court to force institutional settings to offer options to people who *could* enjoy the simple pleasure of eating if the necessary equipment, techniques and therapies were available.

Why not tube feeding?

On a personal-enjoyment basis, people who use tubes for all nutritional intake—not just for supplementation—cannot enjoy the basic human satisfactions of tasting and swallowing. Even if they can taste, but do not swallow food, this is not very satisfying.

Physically, the process of tube feeding is limiting. During mealtime, the person is connected to tubing that is often connected to a stand or pump, which can limit activity and movement. If there is continuous flow of formula throughout the day, the body is taking in food and digesting it all the time. The normal rhythms of eating, absorbing nourishment, building up energy, using that energy and resting do not exist. In addition, if the tube or equipment is visible, others sometimes perceive the person as disabled, sick, or less valuable than others.

About This Series

This is the final in a series of five articles on enteral feeding. The earlier parts of the series include:

- Part One: When a Child Needs to Get Meals by Tube. August 1996
- Part Two: Care of the Stoma and Tube, September 1996
- Part Three: Nutritional Needs, October 1996
- Part Four: Therapeutic Positioning, November 1996

Oral eating is, in itself, helpful developmentally. It provides practice in the movements needed for speech.

Finally, the liquid enteral diet can cause a digestion problem. Gastroesophageal reflux —when the contents of the stomach, including stomach acid, back up into the esophagus—is probably more likely to occur with a less-dense, totally-liquid diet than with a semi-solid diet. If this occurs often, it can cause pain and damage the esophagus. As a result of either condition, the child may refuse to eat altogether, whether or not he or she is capable of doing so. Also, although there have been many technical advances in formulas today, a totally-liquid diet does not provide the gastrointestinal tract with bulk and mass for optimal ebb and flow—emptying and filling movement—and ongoing muscle stimulation and contraction necessary to prevent constipation or diarrhea.

In the final analysis: If there is a way to wean children from tube use, they deserve to have that opportunity.

The oral motor specialist

In reassessing a tube-feeding situation, the key question is *can* the child eat orally safely. The definition of "can" is a very complex one. It involves the child's body—muscle tone, positioning and response techniques—as well as outside influences such as medications that can inhibit or enhance what the child can do.

The role of the oral motor specialist—a speech pathologist or occupational therapist with special training—is to assess the muscle skills and responses of the child to determine what skills are present and what skills need to be developed. In addition to observing the child's oral movements during eating and when at rest, this therapist must assess specific components of movement. These components include how far the muscles can move (the range of movement), the strength of movement, the variety of movement, and the response to pressure and movement of the lips, cheeks, jaw, tongue and roof of the mouth.

The oral motor specialist may also find abnormal patterns, such as lip and cheek retraction (involuntary movements that create a "fake smile"), tongue thrusts out of and into the mouth, and "tonic bite" (a sudden clamping down onto an object inserted into the mouth). When abnormal patterns are identified, the therapist may be able to work with the parent to increase the function of the oral areas in need of development so that the child can respond with better controlled muscle movements. These movements are needed whether the child moves to oral intake or not, since control of secre-

continued on page 36

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continued from page 34

tions (saliva and mucus) remains an area of concern even for those children remaining on non-oral intake.

In addition, the oral motor specialist may assist in determining the structure and function of the areas not visible from the outside, such as the pharynx and esophagus, through the use of x-rays—which could be known under a number of names depending on where the x-ray is taken: modified barium swallow, therapeutic swallow, rehab swallow. If problems are identified in these internal areas, the therapist will work with the parents to help the child overcome them.

It is important to remember that the question to be answered from this x-ray study is, "Can the child swallow safely and effectively, under the best of conditions?" We are not asking if the child aspirates (breathes food or fluid into the airway when he or she swallows). Any of us may aspirate under the worst of conditions, such as lying on one's back when eating. Readers of the most recent article in this series (November 1996) will understand that if the child is not positioned well during the x-ray procedure, he or she may have difficulty swallowing. X-ray suites often do not have child-sized equipment that fits under the x-ray machine, so it would be easy to get an abnormal modified barium swallow result when specialized positioning equipment is not available.

Because oral motor therapy is relatively new for children with disabilities, this particular x-ray procedure for this particular purpose is often an unfamiliar one for the staff conducting it. Prepare for the x-ray appointment in advance with the oral motor specialist. He or she will help you identify what your child needs, in advance, in order to get a valid test result. The oral motor specialist can also determine such things as texture, consistency and the amount of food/barium mixture to give, during the study.

During therapy, as the child progresses toward oral intake, the specialist assists with determining safe and efficient strategies to develop the necessary oral movements.

The oral motor specialist is a relatively new arrival on the speech and occupational therapy field. Many health professionals may not be aware of this development. To find out more about the specialty or to identify specialists in your area, call:

- American Speech-Language-Hearing Association
  10801 Rockville Pike
  Rockville, MD 20852
  (301) 897-5700 (voice or TDD)
- American Occupational Therapy Association
  1383 Piccard Drive
  P.O. Box 1725
  Rockville, MD 20849
  (301) 948-9626

The weaning process

The movements required for eating begin before birth and set the stage for further development. These movements include up-and-down jaw movement, sucking, swallowing and breathing in a rhythmical way to balance intake of food and oxygen. For most babies, this happens without difficulty. The baby shows a suckle pattern of the tongue, with a forward/backward movement, and gradually increases the variety of patterns to include a suck (up and down movement), side-to-side movement, and then a combination of these movements with lip, jaw and cheek. Each progressive step allows the food ingested to increase in texture (size) and consistency (thickness), and new utensils to be introduced, moving from breast or bottle to spoon, straw, cup and fork.

Muscular movement is part of the story. Getting information to and from the brain is another. The mouth is filled with sensory receptors that are ready and waiting to send information to the brain: pressure, movement, temperature and taste. If the brain does not receive sensory information in a predictable or organized way, what might seem to be a pleasant stimulus may be perceived as threatening to a baby that lacks adequate muscle movement and control. Some stimuli may not be perceived at all, for example a nipple is presented but no suck occurs, as if the volume button for the mouth has been turned to "low." Other stimuli may elicit too great a response for the amount of stimuli presented, for example a light touch to the lip may result in excessive gagging, as if the volume button has been set on "high." These situations are known as "oral defensiveness."

Secretions and other body fluids are also an issue. They include saliva, mucus and vomitus, and can collect or pool in the throat, obstructing the airway or getting into the lungs as the person breathes in. An oral motor specialist, other therapist, or nurse can recommend treatments to help with the ability to cough and expand the chest. Good techniques are ones that increase deep breathing and movement of the rib cage, important for producing a cough that works to remove secretions. If your child is one who has difficulty managing oral secretion, help the child to cough and clear secretions before any attempt at oral intake so that he or she will be able to swallow well without coughing or choking on mucus.

Medications

There are a number of situations or conditions that influence how or whether we swallow effectively. An important one is the type and amount of medication the child takes. Almost all children on enteral nutrition receive at least one medication. In addition to its intended effects, medication can:

- decrease sensation and movement in the mouth;
- decrease alertness related to eating and drinking;
- decrease muscle tone needed for swallowing and postural stability;
- slow stomach emptying, making the person feel less hungry;
- interfere with seizure control.

The pharmacist and/or nurse for the child can research the individual drug actions for each medication taken and determine if the drugs could be affecting mealtime and how to change this situation.

If your child has seizures, he or she probably takes anti-epileptic medication. As he or she grows, you may notice new types of seizures that have not been identified before. Work with your child's neurologist for an accurate classification for the seizures, so that medication appropriate for it can be prescribed at a dosage that affects oral eating as little as possible. One

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aim in doing this, is to try to avoid multiple seizure medications, which can interact with each other and render one or more less effective in controlling the seizures. This kind of interaction can also make your child less alert, as can too high a dossage of a single medication. By working with the child's physician— explaining your goal and expectations about oral eating, seizure control, and medications—progress can be made.

Positioning

The most recent article in this series discussed the impact of positioning—seated and sidelying—on both oral and enteral nutrition. That information will not be repeated here, but it is important to remember that there must be enough postural stability for the child to focus on eating.

Even when your child is able to eat orally, he or she may need special techniques for placement of food or fluid in the mouth, control of flow, and support of the head, neck and oral structures at mealtime. Your oral motor therapist should be able to help you in this area, as well.

The family approach

Maintaining a view of your child as healthy and able, encourages and promotes finding ways to help him or her eat orally. Maintain a normal schedule as much as possible. Have a variety of friends over for activities and visits, and make frequent outings into your community, including restaurants. Avoid a medical look in the child's environment. Find ways to decorate medical equipment so that it blends with surroundings. Use baskets to hold supplies, for example.

Humans were designed by nature to experience filling and emptying of the gastrointestinal tract, beginning at the lips. Many factors influence the structure and function of this complex procedure. The goal is to normalize the function as much as possible, given the chronic or long-term health concerns of the child. Health care professionals, therapists, and families working together can make this happen. **EP**

Lee Barks, R.N., M.N., A.R.N.P., is the president and owner of Developmental Health, Inc., a firm that provides consulting services to rehabilitative and long-term-care programs. She also works as a pediatric nurse practitioner at Pediatrics Plus, a private practice in Orlando, Florida, and as a consultant to the early intervention program at the Arnold Palmer Hospital for Children and Women in Orlando. Lee lives near Orlando with her husband and teenage son and daughter.

Debra Beckman, MS, CCC-SLP, is a speech pathologist specializing in oral motor therapy for children and adults. Debra has both clinical and consulting practices; she works with individuals and families and also teaches speech therapists and occupational therapists throughout the US and internationally. She lives near Orlando with her husband and two teenage sons.

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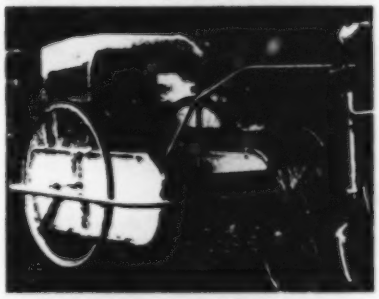

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Chorionic Villus Sampling Birth Defects Registry

The National Institute of Child Health and Human Development has awarded us a grant to develop the Chorionic Villus Sampling Birth Defects Registry. The purpose of this registry is to obtain more information about chorionic villus sampling (CVS)-exposed children with any type of hemangioma or birth defect. One important question to be resolved is whether there is anything distinctive about the birth defects in CVS-exposed children, in comparison to children with similar birth defects who were not exposed to CVS.

We will be conducting a study to examine children with hemangiomas and/or birth defects. There will be 2 groups of children within the study, one group of affected children who were exposed to CVS and a group of affected children who were not exposed to CVS. We invite parents and physicians to enroll any child who was exposed to CVS and who has hemangiomas or structural malformations into the registry. Study subjects may be selected from children enrolled in the registry. Unexposed children who have hemangiomas or birth defects are also being recruited to become part of the comparison group.

All information obtained will be kept confidential. All expenses for participating will be provided. For further information and referrals, contact Caroline McGuirk, M.P.H., Massachusetts General Hospital, Genetics and Teratology Unit, Warren 801,55 Fruit Street, Boston, MA 02114-2696; fax: 617-724-1911; E-mail: mcguirk.caroline@mgh.harvard.edu, or call our toll free telephone number (888) 287-0738.

Circle #35

Intrathecal Baclofen Therapy for Severe Spasticity

PART TWO

by A. Leland Albright, M.D.

This article is the second in a series on Intrathecal Baclofen (ITB™) Therapy, a new treatment for severe spasticity in children and adults with cerebral palsy or brain injury, as well as spinal cord injuries and multiple sclerosis. In this treatment, the drug baclofen injection is administered through a small implanted pump and tube for continuous delivery into the spinal fluid. The following discussion outlines the surgical procedure. The first segment in this series described spasticity, selective dorsal rhizotomy (a surgical approach), the ITB Therapy approach, and the multidisciplinary team assessment used to determine the most appropriate approach for an individual with spasticity. The third segment in this series (February 1997 issue) will focus on other intervention approaches for spasticity, so that consumers can be more informed about each available option.

Goals for any therapy can differ considerably, depending on the person for whom they are intended. The same is true for Intrathecal Baclofen (ITB) Therapy. It is important for parents, the child (or adult) and the clinical team to discuss treatment goals before beginning ITB Therapy. For one person, improved dressing skills and easier transfers (for example, from bed to wheelchair or scooter) may be appropriate goals. For another, better swallowing and communication abilities will be the focus.

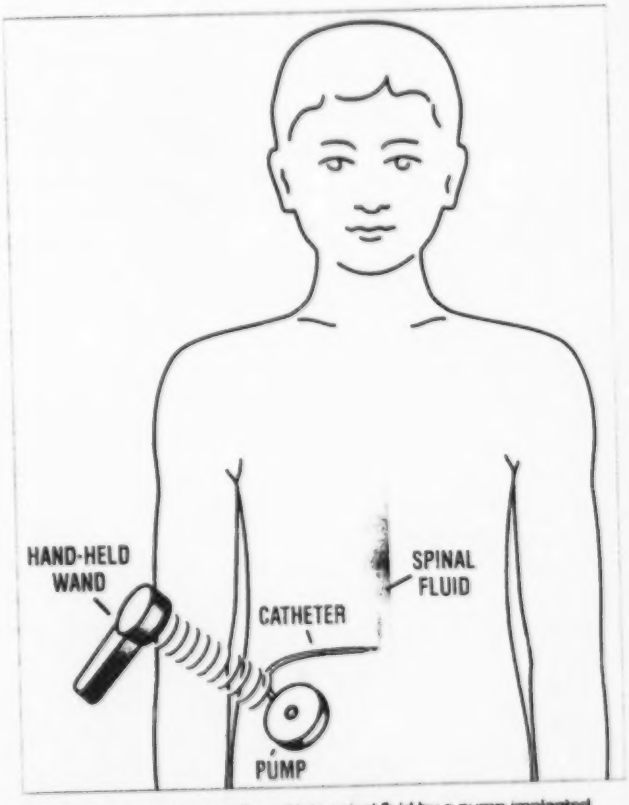
ITB Therapy effectively treats spasticity in cerebral palsy and brain injury because the pump delivers the medication to the site where it is needed. ITB Therapy is adjustable and reversible, and is making dramatic changes in the day-to-day abilities, quality of life and self image of many individuals.

No medication, including baclofen, is effective for every individual. A trial dosage is used to detemine if a person will respond to ITB Therapy. Before a pump is inserted, a test dose of baclofen is injected into the spinal fluid. Approximately 90 percent respond to these trial doses, which relax only the legs. Relaxation from the single dose usually lasts six to eight hours. Because different dosages may be tested, this trial period can last from one up to three days.

Though the trial can be useful in determining the success of ITB Therapy, it cannot predict its outcome. Unfortunately, a test dose will not show how an individual will function during continuous ITB Therapy.

At the hospital

The youngest age at which a child will be considered for ITB Therapy is three. A younger child might not have sufficient space in the abdomen for the pump which measures three inches in diameter by one inch in thickness—about the size of a hockey puck. The pump is put in under general anesthesia. While the operation itself usually takes an hour, the whole process takes about two hours, including administering anesthesia and the time required for waking up.



The baclofen injection is delivered into spinal fluid by a pump implanted under the skin of the abdomen. A computer turns on the pump and programs it to deliver the baclofen.

The length of the hospital stay required for the procedure varies. The shortest stay, however, is four days; the longest is seven. Once the pump is inserted, the child needs to lie flat in bed in the hospital for three days to decrease the chance of

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spinal fluid leaking out and migrating along the catheter tube around the abdomen toward the pump. If there is leakage outside the incision, it can cause infection. Leakage inside the body can cause head-aches and/or vomiting. Then, over the next day or two, the child can begin gradually to get out of bed, sit in a chair and stand. The baclofen dose is adjusted slowly from the beginning of the hospital stay until spasticity is improved. Physical and occupational therapy may also begin at this time.

For two or three days, a child is likely to have a sore abdomen and back. Some children may require pain medication for a few days after surgery. After leaving the hospital, many children require no pain medication, and those who still do, need only Tylenol to handle discomfort.

The pump creates a small bulge in the abdomen. After a few weeks, however, most children seem to be able to ignore its presence . Some modest improvements in function (movement abilities) may be apparent even before a child goes home. Gains in more complex movement activities like writing or feeding or using a computer are likely to take considerably longer: six months or more Caregivers report that care for children who do not have functional abilities is easier with ITB Therapy.

Children with fairly weak muscles before surgery are likely to need physical and occupational therapy to strengthen those that are now looser and have the potential to work more effectively. Depending on the goals for an individual child, the emphasis in therapy may shift in purpose—strengthening muscles and improving specific skills—and intensity.

Follow-up care and pump refills

Once children are at home, they are evaluated by the team at six-month intervals. They also need to visit the clinical team for pump refills—how often depends on the dosage of baclofen needed. A child on a large dose may need to come in on a monthly basis; a child on a small dose, every three months. On the average, refills are needed every two months. When the pump is inserted, it is programmed (according to the doseage each day) so that it will begin beeping softly a few weeks before it will be empty (the beeping can only be heard in a quiet room). Parents will have been informed of the day when the pump needs to be refilled. The beeping is a reminder.

The visit for refilling the pump is brief, taking up to fifteen minutes. The clinician cleans the skin around the pump and inserts a needle through the skin to inject new drug into the pump resevoir. Very few children have problems with this procedure. Some clinicians use a topical anesthetic on the rare occasion when it is necessary.

During these visits, team members will check on the child's muscle tightness and talk with parents about their observations on the child's progress. Depending on these observations, the baclofen dose may be altered. The pump could be programmed to automatically deliver different dosages at different times of the day. If, for example, the child's muscles seem tighter after sleeping, the dose may be increased for several hours before the child wakes up. It is technically

continued on page 40

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Circle #23

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possible to adjust the pump several times during the day, though currently such frequent adjustments are not made.

Usually, the baclofen dose increases slowly over the first year as a result of typical bodily changes and remains relatively stable for years thereafter.

Costs

The total cost of the implant procedure, including the cost of the device, the catheter and hospitalization can range from $20,000 to $25,000. A new pump and catheter costs $7,500 to $8,000. The cost of refilling a pump is about $500, including the doctor's office visit. Thus far, most health-insurance companies have covered these costs. A pump lasts about four-to-five years before it needs replacing.

Possible risks

Potential risks of ITB therapy include those involving the implanted pump and tube. For example, the tube may move, kink or break, or part of the pump may fail to work. In five percent of the procedures that have been done, resulting infections required temporary pump removal. Such symptoms usually occur if the dose is higher than the person needs and no longer persist after the dose is decreased.

Side effects from the drug baclofen itself are usually temporary and manageable by adjusting the dose. The most common side effects include loose muscles, drowsiness, nausia, headache and dizziness. Overdose, through rare, could lead to breathing problems, loss of consciousness, reversible coma and, in extreme cases, could be life-threatening. The very few times things like this have taken place, however, the children get better and are able to return to using ITB Therapy.

Not for everyone

No one treatment is appropriate for everyone with spasticity, whether it is due to cerebral palsy or brain injury. ITB Therapy does not help individuals with low muscle tone (often described as floppy muscles), chorea (uncontrollable, small, jerky types of movements of toes and fingers) or athetosis (involuntary movements of face, arms, trunk). ITB Therapy may improve dystonia (slow twisting, repetitive movements of arm, leg, trunk). Baclofen's effects on dystonia are currently being studied.

The third article of this series will be published in the February 1997 issue. In it, the various approaches to intervention for spasticity will be discussed, so that parents and professionals can be more informed about each available treatment. **EP**

A. Leland Albright, M.D. is chief of the Department of Pediatric Neurosurgery at the Children's Hospital of Pittsburgh. He also serves as Professor of Neurosurgery at the University of Pittsburgh School of Medicine. He is the leading researcher in Intrathecal Baclofen (ITB) Therapy in the United States.

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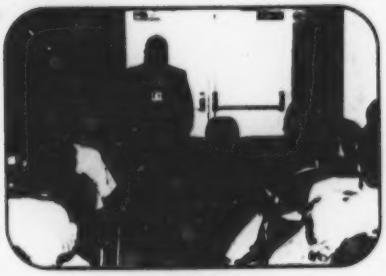
Forum '96 Scrapbook

EXCEPTIONAL PARENT's first conference and exhibition, Forum '96, was a fun time for parents, children, professionals, adults with disabilities, exhibitors and EXCEPTIONAL PARENT staff alike! Thanks to all who participated. We hope to see you next year at Forum '97! Until then, here are a few of our favorite memories of Forum '96:

The exhibit hall is bustling with activity, especially around the Flaghouse toy display! Thanks, Flaghouse, for being a sponsor at Forum '96!

Judy Heumann, Assistant Secretary of Education, Office of Special Education and Rehabilitative Services, U.S. Department of Education, informs parents and professionals about educational policies abd programs.

Pediatrician David Hirsch, aka "Ask The Doctor," spoke on a number of topics throughout Forum '96. Dr. Hirsch was also honored as the Exceptional Parent Medical Professional of the Year.



James May, left, Project Director for the National Fathers' Network and coordinator of *Exceptional Parent's* monthly Fathers' Voices column, speaks to parents and professionals in a special workshop.

1996 Exceptional Parent Awards

Exceptional Family of the Year Award

RECIPIENTS: **Kathy and John Salamone,** Oakton, Virginia

Citation: *For making a very special difference in the lives of their own family and many other families via their untiring leadership role to increase the safety of childhood vaccinations, for their courage in continuing to fight against the odds and for winning the fight.*

Exceptional Medical Professional of the Year Award

RECIPIENT: **Dr. David Hirsch,** Phoenix, Arizona

Citation: *For his dedication to quality, family-centered health care for children with disabilities and special health care needs and their family members through his clinical work, his wonderful efforts to educate health care consumers in EXCEPTIONAL PARENT magazine and his advocacy at the state and national level to educate managed care organizations and other providers about the value of good health care for all children.*

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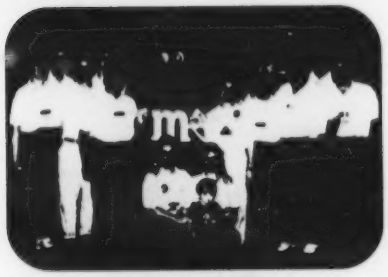
Jim Santos discusses the role of sports and play for children with special needs. Twice named NCAA coach of the year, he is one of the nation's top track and field coaches and an all-around great guy.

Polly Arango, founder of Family Voices, in Algondes, New Mexico, discusses health care for children with disabilities.

Do you have a cavity? Luke Brey, with face-painted balloons highlighting his rosy cheeks, gets a quick check-up from dental students at USC and UCLA. Thanks to both schools for participating!

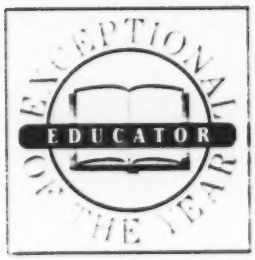


Meet the Exceptional Parent staff! From left to right: Bridget Lyne, Mike Harrison, Roy Whitaker, Marlene Bauer, Tony Arnone, Big Blue M&M (an honorary member), Tracey Habich, Kevin Kleinschmidt (attendee), Debra D'Agostino, Terri Sutera, Joe Valenzano, Doris DeFina, Sandy Scheps, Larry Qualiano, Greg Medara.

R.J. Cooper, a dealer of specialty computer software and hardware, talks with parents and children about their technology questions.

After speaking on the future of educational programs for people with disabilities, Judy Heumann shows Isabelle Castle how to use her powered wheelchair.

Isabelle Castle visits the vision screening pavilion for a quick examination. Thanks to the students at South-ern California College of Optometry for helping us with this event!



Exceptional Educator of the Year Award

RECIPIENT: **Leo Sandoval,** *Director, California Department of Education's Special Education Division,* Sacramento, California

Citation: *For outstanding leadership during his tenure as Director of the California Department of Education's Special Education Division, for his clear and consistent demonstration that he knows that families are the "cornerstones" of every child's education and that parents of children with disabilities and special health care needs are critical team members, decision makers and partners in planning, developing and implementing education plan for their children.*

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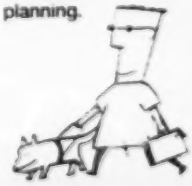
Richard Fee, Director of Education, State of Idaho school for the deaf and the blind, conducts a workshop on estate planning.



Exceptional Non-Profit Organization of the Year Award

RECIPIENT: **NORD**
(National Organization for Rare Disorders),
New Fairfield, Connecticut

Citation: *For pioneering efforts to reach out to families that include a family member with a rare condition, for enabling people throughout the world to advocate for themselves and for their loved ones, for educating health care professionals and researchers, and for making a difference in the lives of thousands of people of all ages.*

Corporate Awards

RECIPIENTS: **AT&T, Ford, Chrysler, Nike, Sigma-Tau Pharmaceuticals, McDonald's, Microsoft, JC Penney, American Airlines and General Motors.**

Citation: *For setting a caring example for corporations large and small by encouraging and supporting the inclusion of people with disabilities and their family members as active participants in everyday life in the community.*

EXCEPTIONAL PARENT wishes to thank all corporations who donated gifts and prizes to all who attended Forum '96, especially:

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Congratulations to all the lucky Forum '96 prize winners:

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Sue Anne Morgan, Avondale Estates, Georgia
J.T. Hiatt-Lough, Long Beach, California

Five-inch black-and-white TV, courtesy of Vail Products:
Katie Mirabito, Norwich, New York

Rock N Roll Cycle, courtesy of Rock N Roll Cycle:
Debbie Bohn, Elgin, Illinois

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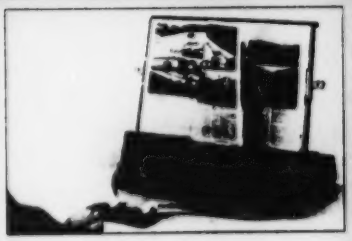

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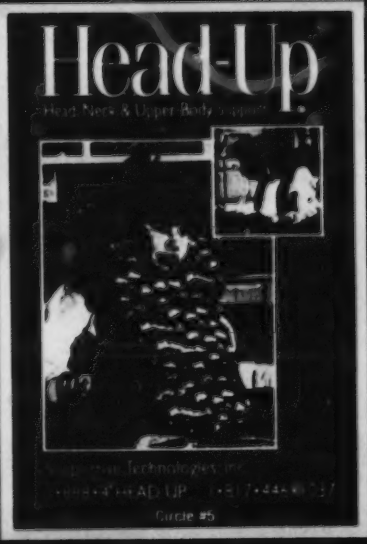

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Circle #6

SEARCH

continued from page 8

Daily Stomach Pain

I've been to many health care professionals about this problem and continue to be frustrated. My five-year-old son has never eaten many foods, including meats, fruits and vegetables. When I finally got my doctor to realize there was a problem, he was diagnosed with reflux and severe esophagitis. After almost two years of very strong medical treatment, he had the surgery done to fix the reflux. It's been ten months since the surgery and he still has daily stomach pain caused by excessive acid. The doctors, including a G.I. specialist have no idea how to help him. He is taking Prilosec and Propulsid daily. He is five and lives only on carbohydrates, peanut butter and a few other foods.

His sister, who is 10, has also had excessive acid in her stomach all her life. It does not affect her eating as it does her brother but it does give her daily pain. I have taken her to several doctors who diagnosed her with a lactose intolerance. But keeping her away from all lactose did not seem to help. I finally got her to another doctor who did a lactose intolerance test which revealed severe esophagitis, so they're assuming she also has reflux, even though three upper gastro-intestinal series and a P.H. probe did not show reflux.

I hope someone else can help us find out what is causing two of our four children such incredible pain.

V. M.
Fresno, CA

Grandparent Neglect

I have a problem with my mother-in-law. She does not accept my 19-month-old child, who has cerebral palsy. Since her birth, she hasn't come to visit her, although she lives less than one mile from our home. She does not call, or check on her when she sick. This makes me really mad and hurt, but this hurts my husband even more. My child doesn't know her grandmother at all. The grandfather is deceased.

When confronted, my mother-in-law states her "wagon is loaded" since her daughter, son-in-law and their one year-old baby depend upon her to support them. It's so hard for my husband and myself to see her with their child—loving, caring and bragging about her. She won't even speak of our child, or display pictures we give her because she is ashamed of her condition. I don't understand a person not treating handicapped children equally, but I am astonished that a grandmother could feel this way. I hope someone give me some advice to help me to understand her.

R.W.
Mississippi

Fetal Hydantoin Syndrome

I have adopted a young adult who has been diagnosed with Fetal Hydantoin Syndrome and grew up in foster care. She is hyperactive, has violent outbursts and has been on psychotropic medications for years. I am unable to find any information on health and behavioral characteristics related to this syndrome and am interested in corresponding with other parents or anyone who has information on this condition.

L.F.
Valrico, Florida

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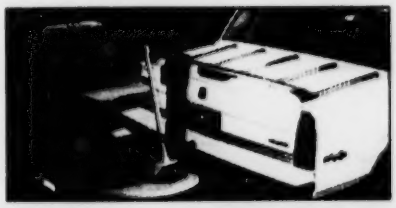

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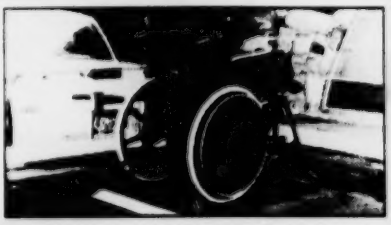

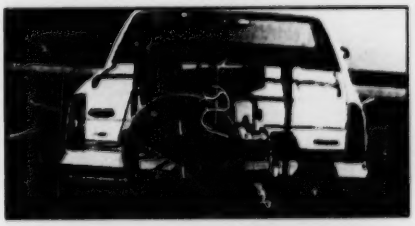

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Circle #36

1089

A Community Welcome

Love is the most important thing.

by Jonathan Rhoads

The birth of our son, Alan, was a joyful, long-awaited moment—our first child! But we soon noticed he had problems, especially that he wouldn't nurse and seemed unable to suck or swallow. Soon we had to rush him to the Albany, New York Neonatal Intensive Care Unit.

With the help of a feeding tube Alan turned the corner and began to gain weight. Eventually we could bring him home, but the hardships were not over. Feeding was still a long battle, and our pediatrician was concerned about Alan's hearing, his nearly-closed eyes and his hips.

We kept taking Alan to Albany for one test after another. At three months he was admitted for 10 days of extensive tests, including an EEG. The specialist was blunt: "Your child can't see or hear, he won't walk or talk, his brain is not normal." We were stunned and heartsick.

But Gretchen and I are fortunate—we live in the Bruderhof, a Christian community where each child is welcomed and loved by all. After those long 10 days in Albany, we could come home and share our need with brothers and sisters: our pastor, Christoph Arnold, and his wife, Verena; our community doctor, Milton, and others.

We felt enfolded by the love of this family of families. It was just 100 days until Christmas and Christoph called the community together for a special meeting to welcome Alan home from the hospital. The children, as well as all the grownups, were invited to help celebrate his arrival. Three busses of people from our sister community eight miles away also came. The meeting room was lit by candles and in the middle was a small, lighted Christmas tree. By the tree, a candle was specially lit for Alan. Everyone waited expectantly, singing one Christmas song after another.

When we walked into that room we felt a pouring out of love and support. Alan was hungry and tired, so we fed and comforted him while we listened as our pastor spoke to us with fatherly compassion, easing our pain and giving us new faith. His words were so encouraging that we wanted to share some of what he said with other parents in similar situations:

"Now the main reason we are here tonight is the great joy of having Jonathan and Gretchen's little Alan with us. Every child is a gift from God, and Alan is a special gift. I plead with everyone, children and grownups, to receive him into our community with great love, because he has been given to his parents with multiple handicaps.

"The doctors told us that Alan is possibly deaf, very likely blind, has brain abnormalities and we don't know if he will ever walk or talk. That's how it

looks now, but with God everything is possible. Love is the most important thing and if any child ever needed love, it is Alan. It is through that love that he will flourish. Even medical studies have proven that love and security can cause miracles.

"So, dear Jonathan and Gretchen, you should feel yourself very fortunate to have received a child like this because he is a messenger of God. Through your little Alan, God wants to reveal a mystery which otherwise would not be shown...you will learn love and compassion for the weak ones, the disabled, and the elderly. So see Alan as a gift from God and thank God for him every day. Never, never accuse yourselves. You should actually sing songs of praise to God."

Christoph had known it would be difficult when people asked "How's Alan doing?" and we did not know what to say. We felt so relieved that now everybody knew of Alan's fight and could support him. These words gave us our direction.

Christoph took Alan in his arms and we prayed together, thanking God for this little boy, trusting him to God's will, whether the miracle of healing or bearing the handicaps. We

continued on page 50

In the spirit of the season, Jonathan Rhoads, his family and neighbors extend the hope that all faith groups will learn from the public expression of welcome his sone received from his community

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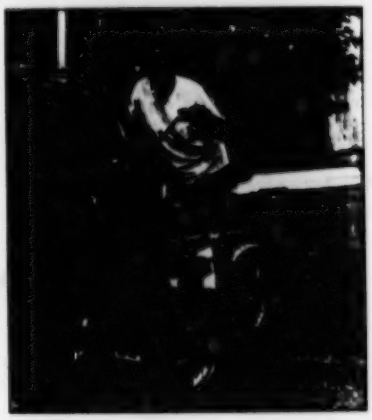

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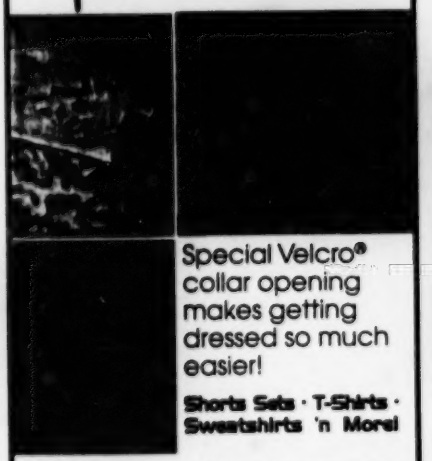

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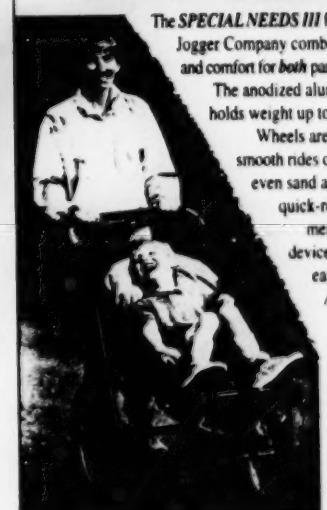

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Circle #10

continued from page 48

believe miracles can happen, but we put Alan in God's hands, knowing that his will is the best for Alan and us all. When Christoph gave Alan back to us, he encouraged us to look with hope to the future.

My youngest brother, Samuel, sat on my lap as close as he could get to his new nephew. After the last song, many other children crowded around us to touch Alan's cheek or stroke his hair. This meeting was so positive, so encouraging. The entire community was so supportive.

We want to pass that message on to other parents of special children. It is hard sometimes because you face so many unknowns, but we are learning to take one day at a time, not trying to predict the future.

The doctors cannot tell us any specifics yet. Alan will just grow and develop in his own way. A lot of that depends on how we care for him at home. So we just enjoy him, like when we give him a bath in the big tub, watching how he enjoys the water. There are times when we are at our wits' end when he's fussy, but then we remind each other of the joyful times. It is important in the low times to talk to somebody, sharing lifts the burden.

We want to make a joyful home for Alan, rejoicing over him every day, showing him lots of love and doing a lot of praying. We want to make it a very special Christmas for our family: the first one that we are a family of three. **EP**

Jonathan, Gretchen and Alan live in the Bruderhof communities, a group of families and singles living in Christian community, sharing all things. Christoph and Verena Arnold, also members of the Bruderhof, are parents of eight children, and grandparents of twelve. Christoph Arnold is the author of several recent books on children and family life.

Fathers' Voices is a regular feature of EXCEPTIONAL PARENT *magazine. This column, usually coordinated by James May, Project Director of the National Father's Network, focuses on fathers' experiences rearing children with special needs. Your contributions to this column are encouraged.*

For more information about the National Fathers' Network (NFN) or to receive their newsletter, write or call: National Fathers' Network, The Kindering Center, 16120 N.E. Eighth Street, Bellevue WA 98008, (206) 747-4004 or (206) 284-9664 (fax). Funded by a Maternal and Child Health Bureau grant, the NFN provides networking opportunities for fathers; develops support and mentoring programs; and creates curriculum promoting fathers as significant, nurturing people in their children's and families' lives.

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Children's Specialized Hospital

Circle #12

1093

BEST COPY AVAILABLE

Finding Respite Care

by David Hirsch, M.D.

Q I am a single parent with a 13-year-old son who has cerebral palsy and epilepsy. Unfortunately, with no close family here, I am his sole caregiver. My son can be difficult to feed and has seizures about three times a week.

Fortunately, I have a wonderful neighbor who watches my son on school holidays and when I am late returning from work. When he is too ill, I stay home to take care of him.

I feel uncomfortable relying on the generosity of my neighbor but I have not been able to find any other affordable, reliable caretakers for my son. I want to take night courses at a local community college to prepare for a career in physical therapy. I would also like to be able to go out with friends. I feel guilty, but I really need some "R and R" and answers about respite care. How do I go about finding and qualifying for respite services? How much am I entitled to? What kind of care can I expect? What kind of questions should I ask? How can I prepare my son for new caretakers?

A It is not unusual for parents to tell me they feel guilty or are reluctant to ask for or use respite services. I ask them to take a self test (see page X) developed in 1989 by Carol Valdivieso for the NICHY News (National Information Center for Children and Youth with Disabilities). If they answer yes to any of these questions, I suggest they can benefit from respite care.

Your need for free time is perfectly reasonable and your desire for advanced education is admirable. You should not feel guilty. Using respite services will give you more energy for parenting by allowing you to take care of your personal needs and aspirations.

Respite care is short term care provided to individuals with disabilities to give families a break from the daily routine of caregiving. It is not typical child care because the person being cared for has special needs that may be complex. Respite care may also involve overnight care for an extended period of time.

Respite care, always very important in caring for individuals like your son, is becoming even more so as a growing number of children with complex disabilities are being cared for at home. Society expects the parents to provide all the care, often without adequate support. Parents, on the other hand, need "R and R" (rest and relaxation).

The availability of respite-care services varies from state to state.

In Arizona, where I practice, case managers from the Department of Developmental Disabilities are responsible for assigning respite-care hours, usually through organizations who provide trained personnel. Eligibility for services is determined on the needs of each case. Respite-care services may be provided for as little as a few hours to over 60 hours per month. In other states the availability is significantly restricted. The organizations listed below should be able to help identify what is available in your state.

ARCH (Access to Respite Care and Help)
(800) 773-5433 (phone)
E-mail:HN4735@connectinc.com

Parent Training and Information
(703) 684-6763 (phone)

The Arc (National Headquarters)
(817) 261-6003 (phone)
(817) 277-0553 (TDD)
E-mail: thearc@metronet.com

Respite care may also be available from state and local organizations such as churches and schools. Charges, if any, would depend on the type of service and who is providing it.

When using respite care services, you need to be comfortable with the individual providing the care. Interview the respite provider well in advance of starting services and ask for references. It is important to make sure the respite provider has had the necessary experience and training required to take care of your son's special needs. It is also important to know how and by whom the respite providers are supervised and what procedures are in place for emergencies, especially medical emergencies. You should expect no less than the quality of care necessary to keep your son comfortable, safe and happy.

It may take some time for your son to get used to the provider and for the provider to win his trust. Since he has learned to trust the school staff as well as your neighbor, it should not be a major problem for him. You may wish to

continued on page 52

In this column, David Hirsch, M.D., a pediatrician and member of EXCEPTIONAL PARENT's Editorial Advisory Board, answers questions from readers. Dr. Hirsch is a partner in Phoenix Pediatrics, Ltd., in Phoenix, Arizona. He specializes in treating children with developmental disabilities and chronic illnesses.

Since Dr. Hirsch has not examined the child in question, parents need to review his suggestions with appropriate professionals. Mention of specific products or medications illustrate suggestions; he is not endorsing any specific products.

Send questions to: ***Ask the Doctor,*** *EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6598 (fax).*

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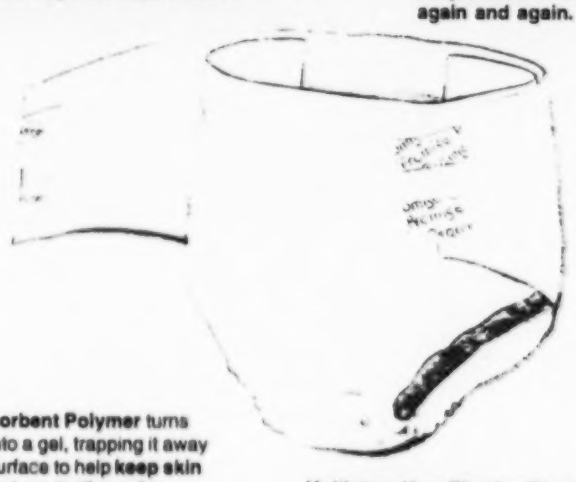

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Circle #34

ASK THE DOCTOR

Can You Benefit From Respite Care?

- Is it difficult to find temporary care for my child?
- Does caring for my child interfere with scheduling appointments or with personal projects?
- Is it important that my spouse and I enjoy an evening alone together, without the children?
- If I had appropriate care for my child with a disability, would I use the time for a special activity with my other children?
- Am I concerned that in the event of a family emergency there is no one with whom I would feel secure with to leave my child?
- Would I feel comfortable having a trained, caring respite provider care for my child?
- Do I avoid going out because I feel I would be imposing on the family and friends who care for my child?

continued from page 51

have the new provider spend time with both of you before leaving them alone together. Another positive aspect is that it gives your son a change in his daily routine and a chance to build new relationships.

Respite care is only one of the support services that may be available to you. Others include crisis intervention, financial assistance, vehicle and home modification, family training, counseling, recreation and, most importantly, case management, which coordinates on an ongoing basis all of these services as well as home nursing, medical equipment and medical issues involving the primary care provider and specialists.

Find out which professional, advocacy, information and parent groups in your area can help. The organizations above are only a start and can help you find out more. They can help you build a lasting and nurturing support network that improves the quality of your life as well as your son's. **EP**

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Circle #33

1095

WHAT'S HAPPENING

Contributions Needed For New Book

Donald Meyer and Patricia Vadasy, authors of *Uncommon Fathers, Sibshops, Grandparent Workshops, The Fathers Program* and *Living with a Brother or Sister with Special Needs*, are writing a new book for grandparents of children with special needs. They are seeking contributions from grandparents about having a grandchild with special needs, as well as contributions from parents and others who know how a child's disability can affect family members.

To obtain a copy of a Contributor's Packet, write The Grandparent Book Project, c/o Donald Meyer, Sibling Support Project, Children's Hospital and Medical Center, PO Box 5371 CL-09, Seattle, Washington 98105-0371. When requesting the packet, please identify yourself as a parent, grandparent, or other family member.

For additional information, visit the Sibling Support Project web page (http://www.chmc.org/department/sibsupp).

Internet Resource For Respite Care

Access to Respite Care and Help (ARCH) National Resource Center, a national resource for respite crisis care services, has launched a web site. The National Respite Locator Service (http://chtop.com/locator. htm) offers information on over 1,400 programs throughout the United States and Puerto Rico concerning respite care. The site also offers informational fact sheets which can be downloaded free of charge. For more information, call the National Respite Locator Service at (800) 773-5433, or write to ARCH, c/o Chapel Hill Training-Outreach Project, 800 Eastowne Dr., Suite 105, Chapel Hill, NC 27514, or e-mail them (HN4735@connectinc.com).

Symposium on Mitochondrial Disorders

Sponsored by the Barnett Center for the Study of Mitochondrial Disorders and St. Christopher's Hospital for Children, the 1997 Symposium on Mitochondrial Disorders is to be held next year in Philadelphia, Pennsylvania on April 4-6. The three-day symposium has two tracks: an international scientific symposium entitled "Challenged in the Study of Encephalomyopathies of Mitochondrial Origin," and a family program designed to educate, support, and facilitate ongoing communication between parents and the medical community.

Parents are required to pay a minimum of $25 of the total cost of $150 per person to attend the conference, but are asked to pay as much of the total cost as possible. For a complete brochure, write the Office of Continuing Medical Education, Allegheny University of the Health Sciences, Broad and Vine, M.S. 623, Philadelphia, PA 19102-1192, or call (215) 762-8263.

Organization for Myelin Disorders

The Organization for Myelin Disorders Research & Support (OFMDRS) has been established. Their mission: to increase awareness about Hypomyelination and Myelin deficient disorders; find causes, treatments, cures and prevention for all children and adults affected by these disorders through education and research; establish a nationwide communication network among affected families, professionals and health care providers; provide support services and assistance, through education, product donation, and resource assistance for families and children that are affected; and provide funding for continual research involving Hypomyelination, remyelination and symptoms or disorders associated with Hypomyelination. For information contact the Organization for Myelin Disorders Research and Support, 3928 Youngman Drive, Cincinnati, Ohio 45245. **EP**

FUNNY AS A CRUTCH by Frank Bernard, Jr.

The following travel section contains excerpts of articles specially prepared by ACCESS To Travel for EXCEPTIONAL PARENT Magazine. The articles appear in their entirety in the Winter Issue of ACCESS To Travel Magazine.

ACCESS TO TRAVEL

The Changing Face of Winter

SNOW BOUND

by Bill Fallon

When winter begins, we're all the same: kids and adults rushing to the window to see the first flakes of snow. Pretty soon, however, we settle into two camps. One hunkers down and waits for baseball weather to return, huddled fast near the thermostat. The other puts on the woollies and heads out into the drifts (or even the slush) to make the most of the cold part of the year.

Lately, it seems a lot more people are opting for the woollies.

"Thank goodness we're seeing an influx of people with disabilities on the ski slopes," says Gwen Allard, director of the disabilities ski program at Ski Windham in Upstate New York. "In the beginning, it was odd to see the people with disabilities skiing. Now, people hardly notice."

From ground zero less than a generation ago, the numbers are impressive. Ski Windham will host 500 skiers with disabilities this year, many of whom will ski for three or four days.

Colorado's Winter Park (home to the National Sports Center for the Disabled) will host 14,000 skiers with disabilities this winter and has a budget of $2.6 million.

Untold numbers of kids, teens and adults will do what the cold-weather sports-lovers with disabilities are doing more and more of these days: refuse to submit to only looking at snowflakes from behind the bedroom window. The cities of Buffalo, NY and San Francisco, CA have begun skating programs for people with disabilities. Those with vision impairments—along with their companion skiers—are now regular features on the winter landscape, barely earning notice among other winter-fun seekers. Horseback riding, which has become popular with the kids, is now a winter mainstay, and hiking, snowshoeing and cross-country skiing are reddening more cheeks than ever before.

"People with disabilities want to be treated as equals," Ms. Allard says. "They don't want pity, and we don't pity them."

Few spots on the planet are as lovely as Jackson Hole, Wyoming. The community offers a winter wonderland of activities, including the popular horse-drawn sleighs for the less adventurous. Meantime, at the top of Rendezvous Mountain is one of

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Opposite page: Winter Park, Colorado

Right: Loon Mountain, New Hampshire

America's most treacherous runs, Corbet's Couloir: a double black diamond monster to give an Olympic skier pause. But in 1991, paraplegic Greg Gibbens negotiated the chute on a mono-ski. Between sleigh rides and Corbet's Couloir are a thousand levels of activities, supervised by the Jackson Hole Ski School's Physically Challenged Ski Program.

At New Hampshire's Loon Mountain, one veteran instructor of the White Mountain Adaptive Ski School puts it this way: "I love to ski, and I love sharing the fun and excitement of the sport with others. It's amazing how many of my students—whatever their situation—learn and progress. The personal satisfaction I feel after each lesson is incredible."

Hal O'Leary

Just about every area of interest has its guru, and in the world of winter sports for people with disabilities, that tag falls to Winter Park's Hal O'Leary. Twenty-six years ago, Mr. O'Leary was another burned-out ski instructor. "I was bored," he says. "It was a treadmill."

Then the phone rang. A group of kids from Children's Hospital in Denver—mostly amputees—wanted to try skiing. Hal volunteered. He failed miserably.

"I was condescending," he says. "I was feeling sympathetic. One eight-year-old fell down. He was whining. His glasses were falling off his nose. And he looked up at me and said, 'I hate your guts.'"

It was an education in the quickest sense of the word. By afternoon, the condescension and the sympathy were gone. And lo and behold, the kids started skiing. "By the end of the day, that eight-year-old said, 'Hal, I really don't hate you.'"

One thing these resorts have in common is their use of winter-fun to break down barriers, internal and external. Sure, a sleigh ride is fun, and a run down the beginner's slope is a thrill. But those who work in the field talk about something deeper. On Hal O'Leary's wall is a poem a woman wrote to him: "You took this troubled heart/Released my spirit."

For Windham's Gwen Allard, an experience with a blind skier comes to mind. "We basically acknowledge their accomplishments and reinforce their strengths—exactly the same as with other students. I had a blind person say skiing was the first time he could remember when someone—a friend or a guide dog—had not been tugging on him. He said he could move and ski where he wanted."

If the image of a blind skier careening down the mountain is a little terrifying, Ms. Allard says there's nothing to it. They use an audible code to direct the skier. She says one of her tasks is to convince cautious parents to let their kids ski in the first place. Forty-percent of her students are children. Once she's convinced the parents, the kids love it.

As with anything, disabilities vary, and so do obstacles and solutions. But there are solutions. For skiing, there are any number of adaptive mechanisms, from "bras" that keep ski tips from crossing, to mono-sit skis that can turn on a dime. Windham's Allard says the first generation of equipment is akin to the "Model A" compared to the titanium-framed rigs on the mountain today.

With advances in technology and awareness, resorts nationwide rush to garner a piece of the disablity market. In this case, however, sincerity does not appear to be lost in the entrepreneurial rush to do business. Most programs rely on volunteers to some degree. As Hal O'Leary puts it, "This program offers self worth. It's the ability to say, 'I can be as dynamic as the next person." A

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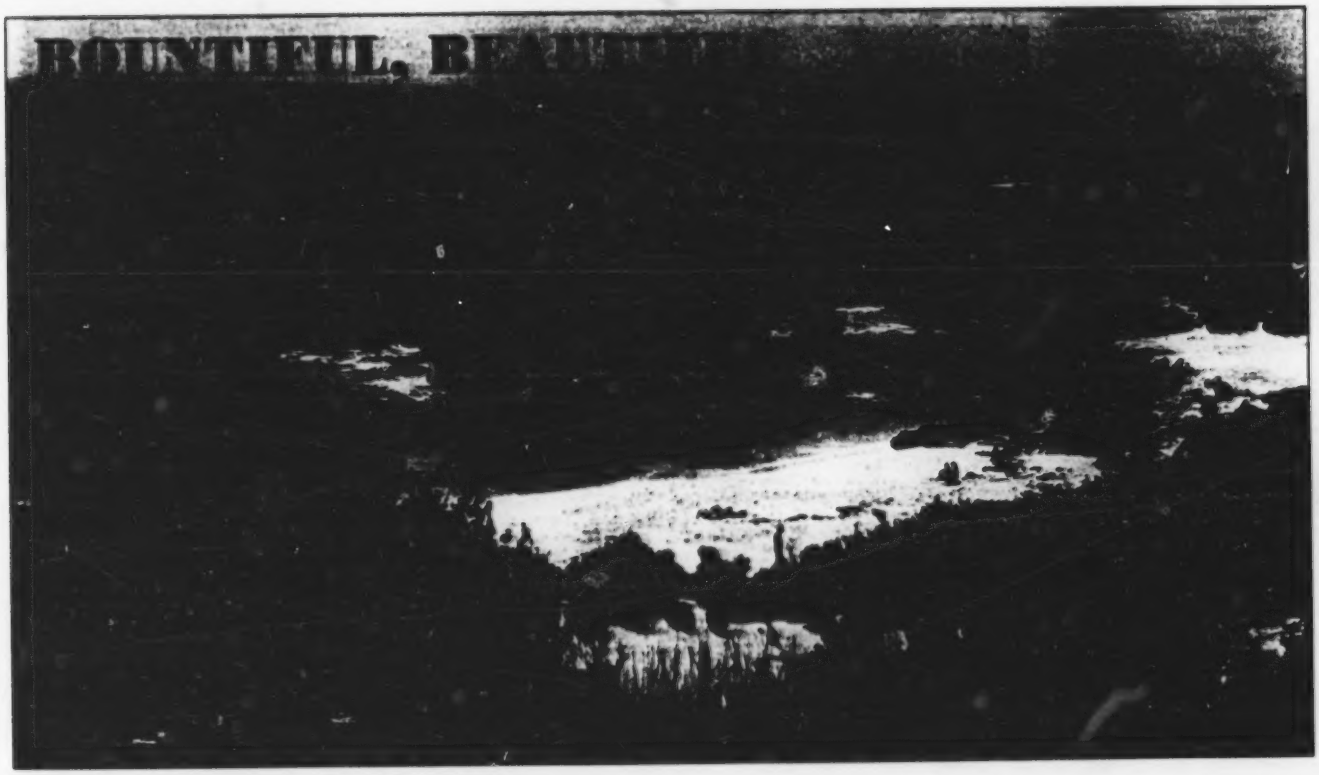

Once a Penal Colony, Now It's a Great Escape!

by Rosemarie Kasper

Returning to a favorite destination is always a dicey affair. In this case, I was eager to see what, if anything, had become of Bermuda in the 19 years between my first and second visits. The world had certainly changed—that much I knew—but what of this island paradise 560 miles east of North Carolina? Bermuda for me was a place of timelessness, of politeness. It was as if natives and visitors alike were aware they shared a child's secret. Shhh! No one else knows this is here.

My trip 19 years ago began with a case of mistaken identity that led to the most wonderful tour. My mother and I approached a taxi driver about a ride. The trouble: This fellow wasn't a taxi driver. The Bermuda solution: Since he wasn't busy, he would drive us around the island anyway. Then he set us up with an established guide. For me it was an introduction to the way things work in paradise.

I had bragged to my friend, JoAnn Berkenbush, about this idyllic isle. Although opposites in appearance—she is tall and strong and I am short and use a wheelchair—we both love to travel, and I hoped she would find Bermuda as alluring as I had.

Our plane landed in magnificent 75-degree sunshine and we headed to our hotel, the Hamilton Princess. We chose this hotel for its central location. The Princess is accessible and nearby to shops and restaurants.

It was immediately apparent that Bermuda is as spectacular as ever, and that Bermudians are as gracious as ever. With deep turquoise water, pale pink beaches, and candy-colored houses, the island is a fairy tale come to life. It is surely one of history's unlikeliest footnotes that the British used Bermuda as a penal colony until 1862. ("If it pleases the court, I'd like to plead guilty and be off to Bermuda without further delay.") The language remains English (with a British accent). No passport is required.

JoAnn and I toured by taxi. Our first stop was the Perfumery to pick up some native fragrances. Then we headed to historic St. George, which is among the oldest English settlements in the New World. The Physically Handicapped Association provides a bus to St. George for sightseeing. Attractions include a replica of the ship DELIVERANCE, which arrived in

Top: Typical Bermuda beach scene
Bottom: Rosemarie and JoAnn at Elbow Beach Hotel

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1610. The Town Square and historic St. Peter's Church are also "must sees." Every Wednesday at noon, a Town Crier directs the reenactment of a typical 17th Century day.

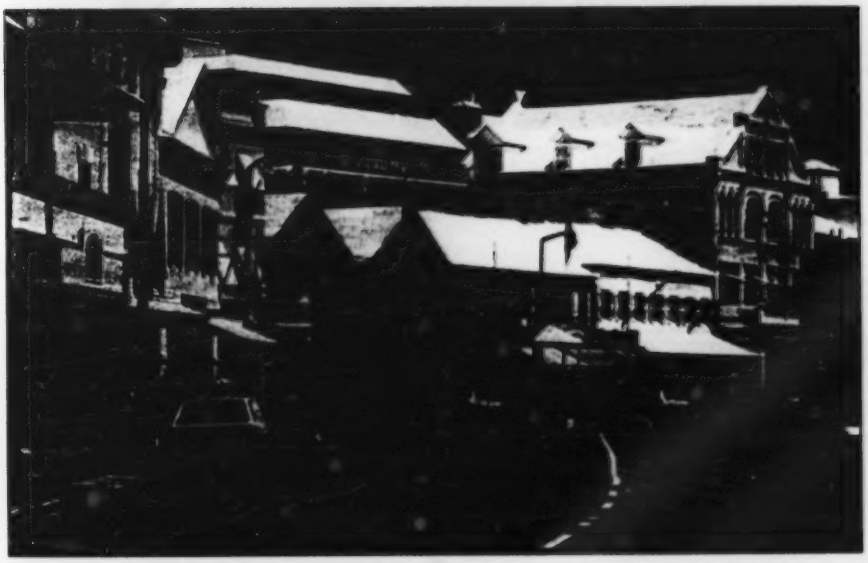
Bermuda's Botanical Gardens are not to be missed. Covering 36 acres, they are reasonably accessible, but hilly. Oleanders, hibiscus, morning glory and poinciana abound. There is the perfumed Garden for the Blind, the Formal Garden, and the Orchid House, to name just a few of the floral treats. While we were there, the Annual Agricultural Exhibition was in progress, so we had the added delight of hundreds of children milling about with assorted cows, pigs and horses.

The Hamilton Princess has both fresh- and salt-water pools. There is also a reciprocal agreement for use of the beach at the sister hotel, the Southampton Princess.

We headed by taxi to the beach, enjoying the beautiful scenery. Bermuda is fishhook-shaped, and just 20 square miles, but it easily makes up in quality what it lacks in quantity. We stopped at Gibb's Lighthouse with its panoramic views of Bermuda and the surrounding water.

It was a dinner at the Elbow Beach Hotel that highlighted the aspect of Bermuda I recalled from 19 years earlier—the unbridled friendliness of the people. We were eating on the deck. I had neglected to bring a sweater. Reluctantly, we asked to move inside, but the waiter had a better idea. Would I please take his jacket, so that I could continue to enjoy the deck? Problem solved— Bermuda style!

Kids of all ages have always been fascinated by Bermuda's famous "glass-bottomed boats." The boats are technically not wheelchair accessible, but the willing Bermudian skippers lifted my wheelchair (and several others) aboard without difficulty. The boats make enthusiastic kids out of everyone, as they reveal a world hidden beneath the waves. There are coral formations—the island itself is coral—beautiful fish, even a shipwreck. When we passed a group of luxury homes, the skipper said, "The taxi drivers live here!"



One of the delights of travel is that the mundane becomes the truly exciting. JoAnn and I went shopping and toured Hamilton with abandon. (Even staid businessmen wear Bermuda shorts.) In the midst of our guilty pleasure (Terrific prices!) we saw another wheelchair user piled high with packages, doing the same thing and enjoying it just as much. I bought a gift and was pleasantly surprised when a piece I'd forgotten was sent, neatly wrapped, to the hotel room. Talk about service!

The only trouble with a trip to Bermuda was that it had to end. We packed and headed to the airport better for having explored this little corner of the Atlantic. I know Bermuda is on all the maps, and accessible from any number of airports and cruise lines, but somehow we feel it is special to us. It seems strangely lost in time—a sweeter, gentler time. Shhh! Don't tell anyone. It'll be our little secret. A

Rosemarie Kasper has osteogenesis imperfecta and has used a wheelchair all her life. She has written for the Christian Science Monitor and the Dallas Morning News and is a veteran world traveler. Her adventures—from high tea in British Columbia to braving the mosquitoes of Alaska's interior -- are a regular feature in ACCESS To Travel. She lives in New Jersey.

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Editor's note:

Exceptional Parent is proud to be working with ACCESS To Travel to help parents learn more about travel opportunities for their families. This insert will appear four times throughout the coming year.

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Innovative Products, Inc., Grand Forks, ND 58201

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Kurzweil Educational Systems, Inc., Waltham, MA 02154

Circle #297

TACTILE SYMBOLS

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Mary-Jane Goodrich, c/o Mier Van Der Roh's Home School, Auburn, WA 98002-8310

Circle #296

The ABLEDATA database of assistive technology and rehabilitation equipment contains information on more than 20,000 products for persons of all ages who have a physical, cognitive, or sensory disability. Products are chosen for this page by the ABLEDATA staff based on their specific applicability to or design for children with disabilities. The circle numbers are to be used on EXCEPTIONAL PARENT's "Free Product & Information Card." Readers can circle a number on this issue's card to receive more information on any new product featured above. Please allow three to four weeks for delivery of the information.

For more information on assistive devices or to submit product information for the database (and possible inclusion on this page), contact ABLEDATA, 8455 Colesville Rd., Ste. 935, Silver Spring, MD 20910-3319; (800) 227-0216 (V/TTY); (301) 588-9284 (V/TTY) or (301) 587-1967 (fax).

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Managing Special Needs Trusts

by Theresa Varnet

Q My mother, who recently passed away, left me trustee of a special needs trust for my brother, who is mentally disabled and lives in a supervised apartment program. I do not know how to manage my brother's trust. Do I pay taxes on the money transferred into it? Must I report how I use the money to agencies providing him services? May I make only limited investments? A social worker recently asked to see a copy of the trust. Must I show it to her?

A Your brother is fortunate your mother created a special needs trust that will protect his share of her estate without jeopardizing his eligibility for government benefits.

To properly manage the trust, consult an attorney familiar with trust law. Ensure you do not disqualify your brother from his benefits by educating yourself on their eligibility requirements.

As your brother's guardian or representative payee, you must keep his government benefits, personal savings or income separate from trust assets. Before opening trust accounts, apply to the IRS for a tax identification number. It is important that you *not* use your brother's social security number, or your own, when opening accounts or purchasing investments in name of the trust. You will be required to file applicable federal or state income tax returns. You must keep records of income earned and distributions made. Never commingle money belonging to your brother with trust assets. Doing so could result in a reimbursement claim from the trust for basic care and support.

You must then make sure that distributions from the trust do not disqualify your brother from continued eligibility. If he is receiving SSI, Medicaid or food stamps, you should not disburse trust funds directly to him. These programs allow only a limited amount of monthly unearned income.

Spending money counts as unearned income. Giving your brother $100 per month in spending money means he may loose that $100 in benefits. It is best then to purchase goods and services for his benefit, rather than give him cash directly. Instead of giving your brother $15 for a haircut, write a check to his barber. Identify services your brother needs and have them bill you directly. These services include phone service, housekeeping, laundry services, leisure-time expenses, a companion, private health insurance premiums, and higher levels of dental or medical care.

Ownership and investment

Because states limit the amount of personal property a recipient can own, it is wise for the trust to own personal property bought for your brother. For example, the trust would own, but give him full use of, a stereo, VCR, or computer.

One exception to this is in buying a car. If your brother drives, register the car in his name, ensuring the trust cannot be sued as owner of the car in an accident. The trust can still pay for car maintainance.

Ownership of a car should not affect your brother's benefits. In most states, a car is an exempt asset when used for employment, medical treatment, or therapy. However, if the car is a convenience, most states limit its value to $4,500.

As trust administrator, you can invest trust assets in any reasonable manner. Consult with a certified or chartered financial planner on how to maximize potential trust income. Balance the need to maximize income with protection against risky investments. Be sure investments do not create a stream of income *directly* to your brother (such as an annuity) which could jeopardize government benefits.

Social worker's request

The social worker may have a right to review the trust if she determines your brother's eligibility for government benefits. The state will want to know if trust assets are available to pay for your brother's care and support. The only way to determine that is to see a copy of the trust.

While you do not want to share the trust indiscriminately, some individuals legitimately need to see it in order to keep your brother's funding in place. When in doubt, ask your attorney for direction.

Remember that fees for trust advice and administering the trust are generally allowable expenses. These include, legal, accounting, and financial planning fees. An attorney's services should be used to head off potential problems of the estate and any resulting liability.

Theresa Varnet is a partner with the law firm of Spain, Spain & Varnet, P.C. of Illinois and Massachusetts. Theresa is a master's level social worker and parent of a daughter with tuberous sclerosis and mental retardation.

This material is not to be regarded as providing advice for any individual case. Because regulations vary from state to state, readers are reminded to consult appropriate national association or legal professionals before acting on the advice provided in this column.

Send questions to: Future Planning, Exceptional Parent, 555 Kinderkamack Rd., Oradell, NJ 07649.

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EDUCATION

Puberty Comes Anyway

by Joann Noll

My daughter, Emily, is 14. Like many teenagers, she is a young woman in some respects, a child in others. We began preparing her for the journey through puberty four years ago, when her body first began to change. The onset of puberty reawakened in us the same fears and uncertainties we felt the day Emily was born, the day we first learned she had Down syndrome.

I remember talking with a friend whose nine-year-old son with Down syndrome was also experiencing those bodily changes—"All I can think of when I wake up in the morning is 'Alex has pubic hair.' Why can't his development be delayed in this area, too! It's not fair!"

We experience intense feelings when our children enter puberty. It is not an easy time. In fact, it may be very uncomfortable. A father may have to help his daughter with her bra or sanitary napkin. A mother may have to bathe her adolescent son. The child may have questions about his or her sexuality and disability: "Will I be able to marry, to have sex, to have children?" These questions may be difficult to answer. But our feelings of fear, anger and uncertainty can be worthwhile if they motivate us to prepare our children for this new phase of life.

The Noll family: Steve, Joann, Stephanie, 17, and Emily, 14.

Preventing sexual abuse

When our two daughters were young, we somehow felt we could protect them from all harm. But as they grew more independent, we weren't always there with them. My husband and I became particularly concerned about teaching Emily to protect herself against sexual abuse. Eventually, we realized that this preparation had begun long ago, when we first started encouraging her to stand up for herself.

One early incident stands out in my mind—the time a preschool classmate convinced Emily to color her tongue with a black marker. Her teachers were upset both with Emily and the other child. At home, we talked to Emily about not doing things just because someone told her it was a good idea. We also had her brush her tongue and rinse her mouth until the "evidence" was gone.

By fourth grade, these lessons in "self-advocacy" were starting to take root. In an incident I heard about only after the problem was solved, Emily went to her teacher for help when some boys teased her.

Last year, Emily began taking Tae Kwon Do. Since she can be compliant and soft-spoken, we wanted her to be able to say "NO!" as if she meant it. We felt that learning some self-defense would give her the confidence to protect herself. She now has earned her yellow belt and yells "aaii-yah!" with conviction.

If we are to give our children an opportunity to grow toward independence, we have to be able to trust the people who care for them. Our children need to trust them, too. At the same time, we must teach our children to be prepared for potentially harmful situations. We have used many resources to teach Emily about appropriate and inappropriate touch, and what to do if someone touches her in an unwanted or inappropriate way. We reinforce this message through role-playing so Emily can practice her responses. This hasn't made Emily fearful of other people. Rather, having the knowledge of what to do if such a situation arises has actually helped her feel more confident and in control.

A typical reaction

When her older sister's body began to change, Emily was very interested—much to Stephanie's embarrassment. She wondered when she, too, would get pubic hair and when her breasts would grow. We began to talk about these developments and about menstruation, answering her questions as she examined tampons and sanitary napkins. I realized I would have to lose some of my modesty and desire for privacy in order to help Emily learn what a period looks like, and how we change and dispose of the supplies.

When Emily got her first period, she reacted like many teenage girls—"I don't like it. I don't want it anymore." But Emily's teachers helped her see this developmental milestone in a more positive light. They privately congratulated Emily and told her how excited they were that she was growing up.

continued on page 62

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Emily Noll, 12, (right) clowns around with friends Celia (left) and Angela (center) during a Girl Scout camping trip in 1994.

continued from page 61

Informed and responsible

Some parents fear teaching children about sex will make them anxious to experiment. Yet it is nearly impossible to keep our children from being exposed to strong—and largely inappropriate—sexual messages in the media. Counteracting these messages with the information we want our children to have makes them more responsible about their sexual behavior.

I recently spoke with a young woman who had become legal guardian to her teenage brother. He had no knowledge of sex, other than what he had seen on television. At a sheltered workshop he met a young woman who was most anxious to educate him. After an incident in which the two attempted sexual intercourse at a bus stop, the young man's sister realized she needed to help him understand the consequences and responsibilities of sex, as well as safe and appropriate expressions of affection.

Learning the difference between appropriate public and private behavior is an important lesson, and one that should be taught early. We may have a harder time teaching a child that he or she should masturbate only in the privacy of a bedroom, for example, if we don't reinforce the private-public distinction in personal care matters. More than 10 years ago in EXCEPTIONAL PARENT ("Sex Education and the Disabled," June 1984), Theresa Varnet wrote about this issue with regard to her daughter, Jenny—"I seldom pulled down the shade when I changed her clothes, and I would change her [diaper] in the living room with others present. I did not realize I was teaching Jenny bad habits that would be hard to change when she entered puberty."

"Sex and stuff"

Other parents and professionals helped us understand that even though information is repeatedly presented to children, sometimes the "light bulb" has to go on before they truly understand. This was certainly true when it came to Emily understanding the "facts of life."

For two years, we had read books and talked with Emily about how babies are made, using the appropriate terminology to describe sexual intercourse. Then, one day, she came home from school and said, "I know what sex is." When I invited her to explain, she said, "It's when people

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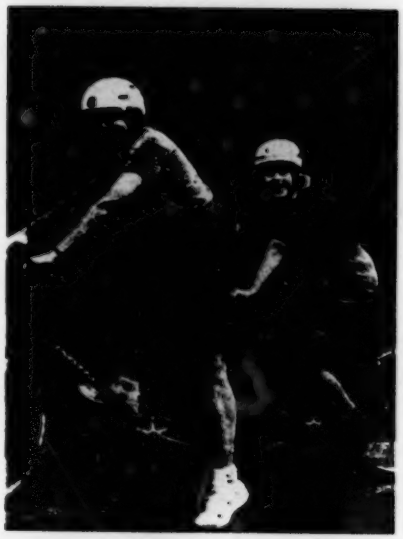
get married and stuff."

I asked, "Do you mean when the man puts his penis in the woman's vagina?" And suddenly, I saw her face light up with understanding! Discussions with friends at school must have contributed partially to her understanding, but she didn't quite get it until I repeated it again.

A few weeks later, we saw a public service announcement in which a 15-year-old girl talks about how hard it is to be a teenage mother and how she should have said "no" to her boyfriend. When I asked Emily if she knew what the girl was talking about, Emily replied, "Sex and stuff."

Good, independent decisions

Emily has the same expectations for love, marriage and children as most other teenage girls. We spend a lot of time talking about the responsibilities and realities of all those life choices. I believe it is important to present the facts, to share my values, to talk about the responsibilities of sexual behavior and to help Emily feel good about herself, so she has the confidence to make good, independent decisions.



Joann and Emily Noll gear up for a mother-daughter bike ride. Besides bicycling, Emily enjoys other sports, movies and reading.

Puberty forces us to think about our children's future, which often looks scary. But I've found that sharing these feelings with other parents has been immensely helpful, both for practical tips and reassurance. We may never really be ready for our children to start growing up, but, alas, puberty comes anyway. **EP**

Joann Noll is Assistant Administrator for Parent Education for the Special School District of St. Louis County. She lives in Webster Groves, Missouri, with her husband, Steve, and two daughters, Stephanie, 17, and Emily, 14. In 1995, Joann was named Parent of the Year by the Missouri Governor's Council on Disability. The Noll family enjoys vacationing, bicycling and camping, but most of all, sharing a few laughs around the dinner table.

For more information on educating your child in these matters, contact the Sex Information and Education Council of the United States (SIECUS) at 130 W. 42nd Street, New York, NY 10036, or call (212) 819-9770.

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Co-edited by Samuel J. Meisels and Emily Fenichel

Eighteen chapters—over 400 pages of the latest approaches to assess and support children's developmental capacities

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New Visions is the **first book** about developmental assessment that speaks to the **wisdom** of the **family**, the **competence** of the **infant**, and the ways in which successful strategies are contingent on our capacity to form relationships with both babies and their caregivers.

-Corinne Garland, Child Development Resources, Norge VA

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COPING WITH CRISIS
Confronting the emotions you fear

by Michael T. Hynan

After my son survived a high-risk birth, I have felt I owe a debt to doctors, nurses, friends, family and other parents who have experienced the heart-break and trauma of a child-at-risk. My payment would come from putting my knowledge of psychology to use supporting others and helping them adjust emotionally to their new role as "high-risk" parents.

Veteran parents of the neonatal ICU battlefield want normalcy to return quickly, but find themselves disorganized and upset for months. Emotions run high: terror, grief, anger, guilt, frustration, jealousy and intense fatigue haunt us—sometimes for years. My message as a high-risk parent and a clinical psychologist: You are doing well, not poorly. These lousy emotions you want so much to go away are actually signs that the natural healing process is underway.

It is reasonable for high-risk parents to experience terror, anger, grief and depression as they cope with shattered dreams. These emotions are not negative; they are signs that parents are coping *well*. What else would you expect from someone experiencing stark terror, nights of grieving, significant depression and extreme frustration?

There is another, more troubling aspect of these emotions: anger with one's own baby for disrupting one's life. One parent, Jennifer, told me her concerns for her husband. Their baby, Jason, had been home for a few very rough months. He had suffered serious brain hemorage. They didn't know if he would develop normally. Jennifer appreciated her husband's strength but was worried. Despite his denials, something seemed wrong. One day she risked opening up to him.

"You know, Dan," she said, "It's terrible, but sometimes I wish that Jason had died during the first few days so we could be over this now." Dan broke into tears—that had been his terrible secret, too. They held each other and cried, finally acknowledging their feelings. After taking this first step, their guilt lessened and they could continue sharing more deeply. Dan let himself feel again and actually enjoyed being a father. Although anger toward Jason sometimes resurfaces, it is less powerful because Jennifer and Dan no longer fear it.

High-risk parents create unfortunate barriers, believing that only other high-risk parents can help them. Perinatal professionals should help parents of high-risk infants cope with by sharing common feelings and being understaning of our experiences. Tell us it is normal to worry. Acknowledge the disruptive panic we feel every time the phone rings at home. Discuss openly the problems we may face when bringing our baby home. Work with us for a strong parent support system and a paid Parent Support Coordinator in your hospital. Most importantly, acknowledge our emotional turmoil and let us know you are not afraid of our feelings.

This kind of emotional support should follow up in the professional community as we take our child home and face the often uncertain—sometimes too certain—future. Our emotions are real, frightening and valid.

High-risk parents frequently make a series of bargains—bargains that seldom come out even; bargains we often lose. "I'll give up my dreams of natural child birth as long as my baby gets healthy and comes home at term." "I'll accept the ventilator as long as my baby doesn't go blind." "I'll accept the surgery, as long as my baby lives." Adjustment means trying to make unacceptable losses acceptable. Giving up lost dreams is necessary so we can resume living as a family with joy.

One father told me how he felt after receiving a phone call at work saying he had lost yet another bargain: his child would be visually impaired. He rushed to his boss and breathlessly requested permission to leave for the hospital. When his boss asked why, he broke down and sobbed. "They've been taking all the pieces away, bit by bit, and there aren't any pieces left."

Although he lost control and feared his boss thought he had lost his sanity, I can't think of a more normal reaction. Blindness was another bitter pill to swallow, but swallow it he did, very slowly and with much regret. To refuse the pill would have meant a life of anger, lawsuits, doctor-shopping, and little joy. To be sure, regret and sadness are part of his life, but acceptance means they are accompanied by joy and love for his daughter and who she is.

High-risk parents know that love means more than holding hands and romantic walks on the beach. It also means blood, sweat, many tears, and feelings of terror, grief, and anger.

As time passes, most families go through the process of accepting their shattered dreams and their crisis resolves. Life has changed; some of it for better, certainly some for worse. They can begin to experience the pleasure of love for their new child and recognize that parts of life can once again be good. **EP**

Michael T. Hynan is a practicing clinical psychologist and associate professor of clinical psychology at the University of Wisconsin-Milwaukee. He is also the author of "The Pain of Premature Parents: A Psychological Guide for Coping" (University Press of America, 1987). Dr. Hynan and his wife, Lauren, experienced firsthand the trauma of a child-at-risk when their son was born at 30-weeks gestation. A member of the National Perinatal Association, Dr. Hynan has long been an advocate for family-centered perinatal care.

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More Than One

by Richard Epstein

Q My daughter is 11 and has cerebral palsy. She was fitted with a manual wheelchair when she was six years old, but because her ability to use her left hand is very minimal she is not able to propel the wheelchair to its full advantage. Although she has had treatment to reduce spasticity, she continues to be non-ambulatory and to require assistance for daily skills. However, she has made improvements in all aspects.

Her doctors and physical therapists now recommend a power wheelchair for independent mobility. She recently had the opportunity to try out a power wheelchair and has not stopped talking about it.

It is clearly stated in my insurance policy that we are only allowed one wheelchair per lifetime. Do I have any recourse? How can they expect a wheelchair that was fitted for her at age six to fit her now when she is 11?

A Some parents have been able to obtain reimbursement for a second wheelchair for their children, even when an insurance policy includes a clause that limits coverage to one per lifetime.

Start by filing a claim appeal with your insurer. If you are insured under a self-funded plan (one established by a company, union, association, or government agency, rather than purchased from an insurance company), send the claim appeal to both the plan administrator and your employer's benefits administrator. Include a letter from your daughter's physician that specifies the diagnosis and current medical condition and clearly explains her need for a wheelchair. Since the request is for a power wheelchair rather than a manual one, ask your doctor to include a statement in the letter that explains why a manual wheelchair does not meet your daughter's needs at this point.

As obvious as it may seem that your daughter both needs a wheelchair and is unable to use a manual one, it is important to meet all documentation-related requirements when you file a claim appeal. Insurance companies often process large numbers of claims each day and the person evaluating your claim appeal may not be familiar with the details of your daughter's situation. In addition, some insurers may not even start to process a claim for a power wheelchair until all the paperwork is in place, including a statement specifying the diagnosis, the medical need for a wheelchair, and an explanation of why a manual wheelchair is not appropriate. The more thorough you are in meeting the insurer's requirements, the more likely it is that the process will go quickly and that the outcome will be favorable.

If your appeal is unsuccessful, there are several other possibilities to consider. First, check with the local offices of the Division of Vocational Rehabilitation Services and the Department of Health. In some states, such agencies may have limited funds for the purchase of durable medical equipment for a child with a disability. If funds are not available directly through those agencies, their representatives may be able to suggest other possible sources.

Second, check with your local public school district. If a piece of medical equipment can be clearly shown as directly related to a child's educational needs, and if the equipment need is noted in the child's Individual Educational Program, the local school district may be willing to consider helping to purchase it.

Third, there are private organizations that sometimes provide grants for the purchase of medical equipment for a child with a disability. The Disabled Children's Relief Fund (402 Pennsylvania Ave, Freeport, New York 11520), for example, will consider providing a grant in such situations. Local service organizations may be another funding source.

You may also be able to purchase a used power wheelchair inexpensively through the local Tech Act program (see "Health Insurance Troubleshooter," May 1996). It's important to remember that there are usually no product warranties or guarantees on used equipment. To obtain information about the Tech Act program in your area, and to determine whether they have an equipment exchange or recycling program, call the Rehabilitation Engineering and Assistive Technology Society of North America at (703) 524-6686, or write them at 1700 N. Moore St., Suite 1540, Arlington, Virginia 22209-1903.

Let me know how things work out. **EP**

In this department, Richard Epstein answers readers' questions about health insurance. Send questions to him at EXCEPTIONAL PARENT, 555 Kinderkamack Road, Oradell, NJ 07649-1517, (201) 634-6570 (fax).

If your question relates to a specific health insurance claim, please include copies of any materials you've received from the insurance company. (Please, don't send originals!) Include your address and phone number, so we can contact you for more information if necessary. Letters cannot be answered individually.

Since regulations differ from state to state, and since state and federal regulations change periodically, it is essential to discuss specific health insurance problems with appropriate state and/or federal agencies, or with an attorney, before taking any actions based on the advice provided in this column.

Caregiving Resourcefully

The National Family Caregivers Association and Mosby Lifeline have just published THE RESOURCEFUL CAREGIVER: HELPING FAMILY CAREGIVERS HELP THEMSELVES. This affordable and user-friendly national resource guide is uniquely designed by family caregivers for family caregivers. The guide's five chapters provide quick access to information, tips and encouragement, covering these topics:

- Caregiver Organizations: Caring for Yourself
- Respite Resources: Taking Time Out
- Hotlines, Helplines: Directories and Databases: Finding Help Fast
- Educational Materials: Learning More
- Home Shopping: Making Life Easier

Beyond the 500 resources listed, THE RESOURCEFUL CAREGIVER offers caregivers support through articles, poems and personal messages from other caregivers. The book is available in bookstores and directly from the publisher, Mosby Lifeline, CQS, Mosby-Yearbook, 11830 Westline Industrial Drive, St. Louis, Missouri 63146, or order by telephone at (800) 426-4545. The price of the book is $12.95, plus state tax and shipping costs, where applicable. It is also available from the EXCEPTIONAL PARENT Library (800-535-1910). The following are excerpts.

The Resourceful Caregiver

What is caregiving and who is a caregiver? We probably all have our own definitions, which may well change over time along with the circumstances of our lives. What we share that someone we care about, someone with whom we have a significant relationship, has been diagnosed with a chronic illness, terminal illness, or disability, and this causes sadness and unsettles the pattern of our lives. This is the essential bond of caregiving.

Caregiving has many different faces. For some of us it means providing 24-hour-a-day care for a parent, spouse, child, partner, sibling, or close friend who can't dress, eat, or go to the bathroom without assistance...For many

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of us, however, caregiving is more of an emotional challenge than a physical one. In some cases, it is a waiting game because a loved one has received a diagnosis of chronic illness but debilitating symptoms have not yet appeared. There are as many different stories as there are family caregivers...Caregiving often means you have more questions than answers; that you put your dreams on hold—sometimes temporarily, sometimes forever...

The National Family Caregivers Association and other organizations...offer support, education, information, and referrals for family caregivers. Many of these organizations were begun by caregivers for caregivers...some organizations help combat isolation; other organizations provide information and educational resources to help you deal with very specific issues. Still others can help you access resources close to home. The organizations noted here are, for the most part, national in scope. We have listed their names, addresses, telephone numbers, and hours of operation. When available, additional information, such as the organization's facsimile number, e-mail address, or Internet web site address, is listed...

In addition to the sources mentioned here, you should reach out to find other organizations. Call the social work department of local hospitals; they often run support groups. Check with you local churches, synagogues, or mosques and your Area Agency on Aging. Remember to call the local office of the health agency focusing on your care recipient's condition; for example, the National Multiple Sclerosis Society or the United Cerebral Palsy Association. Many such health agencies offer services just for caregivers because they recognize that you need help, too.

Remember, caring for yourself is critical to your own continued health and well being.

NFCA's Principles of Caregiver Self Advocacy

1. Choose to take charge of your life.
2. Honor, value, and love yourself.
3. Seek, accept, and, at times, demand assistance.
4. Stand up and be counted.

Each of the Principles will be discussed in more depth at the end of each of the chapters of this book.

We family caregivers can be a powerful force for change in our own lives and in the lives of our loved ones, if we are willing to be our own advocates.

We hope you will use these Principles to take control of your life; to honor, value, and love yourself; and to find the help you need. Stand up proudly and be counted as one of America's family caregivers.

Excerpted from THE RESOURCEFUL CAREGIVER: HELPING FAMILY CAREGIVERS HELP THEMSELVES by the National Family Caregivers Association. Published by Mosby Lifeline. **EP**

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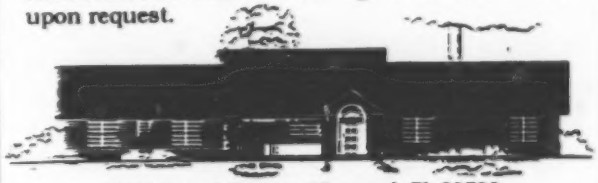

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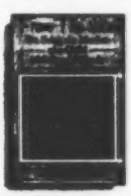

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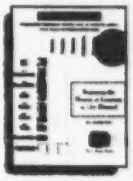

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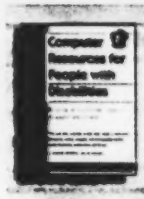

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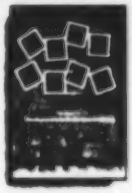

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A Sister Speaks Out

by Jennifer Borkowski

I have a little advice for everyone. If you see a disabled boy or girl, do not stare at them. If you have a disabled brother, sister, nephew, or cousin; do not be embarrassed. When they get bigger they will need help with a lot of things. People will make fun of them.

I have a little brother with Down syndrome. One day I went to school, and a boy in my class was making fun of my brother. I said, "Hey, that's my brother!" He said, "Sorry."

My brother goes to school. He has a lot of fun! His name is Joseph Michael Borkowski. I also have three other brothers. Chris is the oldest. Michael is my little brother and Stephen is my other little brother.

My brother, Joseph, has a lot of problems. He has a hard life. People come and teach Joseph things. They are called therapists.

I cry a lot when Joseph has surgeries. It make me very, very, very sad! I get scared.

People with Down syndrome and other disabilities are the same. They laugh and they cry. But most of all, they all have feelings!

When I am worried about my brother, I will talk to my mom and dad. I will sometimes be sick. I will sometimes fake being sick. It is very hard.

My brother is blind. If you close your eyes, you will get scared if you hit something. My brother is not a normal person. My brother is very hard to teach. But, he sure has feelings. If he bites you, it will hurt. If you say, "Joseph, that hurt me!" he will reach out and give you a kiss and a great big hug.

Please do not be embarrassed. If you think for a while, it is a miracle that God created a new life. God puts disabled children with people who He feels can love and take care of them best. I love my brother. I wouldn't give him up for the world. He is so cute.

If you are embarrassed, talk to someone...it will make you feel much, much, much better. Disabled people have a lot of feelings. If the world did not have disabled children, where would all the love be? Please help people with problems, don't make fun of them! **EP**

Mom's turn:

It was an extremely hot and humid day and all the kids were restless. I told them all to find something to do. Chris, who is 13, was up in his room, reading. Michael, who is 9, and Stephen, 6, were playing Nintendo. Joey, 3, was listening to his Barney tape. Jennifer, who is 11, was up in her room "creating." Unknown to me, she was writing a story about her brother, Joey.

As I read the story, I cried! I couldn't help but think, "Wouldn't this world be a better place for all of our children if people could only look through the eyes of a nine-year-old child?"

Jennifer is a fifth grader at Lionville Elementary School in Lionville, Pennsylvania. She loves cheerleading, and softball, but most of all she adores little children, especially her baby brother, Joey. She is one very special girl!

The Children's Page welcomes contributions from children with disabilities, their siblings and their friends. Be creative! Send your stories, photos and artwork to: Children's Page, Exceptional Parent, 555 Kinderkamack Road, Oradell, NJ 07649-1517.

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